How to be a Proactive Patient

Part III: Question & Answer Session

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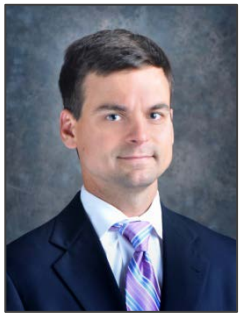
BCAN Patient WEBINAR SERIES

Presented by:



Dr. Stephen Riggs *is currently an associate professor with the department of urology in the Levine Cancer Institute at the Carolinas HealthCare System in Charlotte. He completed his oncology fellowship at the University of California Los Angeles medical center, following this he accepted employment in the department of urology at Eastern Virginia medical center before relocating to Charlotte. He is active in clinical practice in urologic oncology, and that includes a strong interest in clinical trials, surgical outcomes and enhanced recovery after surgery. Dr. Riggs is the director of the Levine Cancer Center Institutes, conferences as well as the urology residency program director. He has authored and co-authored multiple peer review manuscripts, editorials and articles in addition to serving on many local and leadership roles within the field of urology and urologic oncology.*

Mary Dunn *is a nurse practitioner at UNC Chapel Hill. She works in the multi-disciplinary role within urology and medical oncology caring for patients with genital urinary malignancies. Her clinical interests include survivorship and then development and implementation of survivorship care plans as well as palliative care. Mary's one of the founding members of the North Carolina triangle chapter of Beacon and serves on the board. She helps to organize our annual walks and other projects throughout the year and she serves in the triangle oncology nursing society and the triangle chapter of the society of urologic nurses and associates. Mary received her bachelor's degree in nursing from the University of Virginia and her masters in science and nursing from Duke University.*

Question 1: Given the sub-specialty focus required of elite bladder cancer urologic oncologist, why are there no uro-oncologist fellowships devoted specifically to bladder cancer? Why are there no sub-specialty medical society, medical organizations specific to bladder cancer other than BCAN? What is your perspective on that?

Dr. Riggs: I'll be happy to take it. Just to make a couple of comments, urologic oncology it can be one or two years for urologists. Obviously … Not obviously, medical oncologists tend to do general medical oncology and then they sub-specialize in a niche of genital urinary and just to be fair, the pool of patients for specifically advanced bladder cancer or what typically seen by urologic oncologists would not be something across the united States in a day every urologic oncologists now. At the same time people tend to be drawn to certain areas and some folks tend to have more of a bladder cancer or kidney cancer focus, but urologic oncology is a pretty small field to begin with. That training is spread amongst three or four diseases states.

Question 2: In cardiac surgery and joint replacement orthopedic surgery, there are published data relating favorable outcomes both morbidity and mortality to both the surgeon and patient volume, the number of cases that the doctors are seeing a year. Is there similar data out there for a cystectomy? What's the minimum number of cystectomies a year below which a patient should be

concerned in selecting a surgery and a surgeon or a hospital volume overall? I always tell people, you don't want to go to a doctor that says, "Oh, I read about that in a journal once." You want to know you're going to an expert, so are there data out there that patients can find that help them understand a surgeon's experience in a particular area? Or is it something that the surgeon themselves need to provide? Should they provide it?

Dr. Riggs: Yeah, that's a great question. There is published literature that suggests that … It really falls in line with the reference to orthopedic but it's not unique to bladder or orthopedics. Its higher volume centers, higher volume surgeons tend to have better outcomes, but you have to be very cognizant what that means as well. That is not only the surgeon, that's the after care, the familiarity. It's like anything in life. If you do it repetitive over time, you most likely do it better and better and you learn the nuances of it. In terms of finding specifically the numbers, without published reports from those institutions, I don't know that you can specifically find them, so I think you got one of two options.

One, you can search and see if that's reported. There's a lot of places that do publicly report their numbers. The departments or department websites person or urology websites they may not so much pure private practice, but a lot of departments and websites will put out publications per year looking at their cases, their volume, their outcomes, etcetera. Then I think equally, excuse me. That's equally viable is I think if you ask that and you get a very delayed or uncertain response and I think you can start to become clued in to that fact that maybe that's not something they do all the time.

I would probably … if you don't have time to look that up, or you can't find published data on their website then I would just pose that question in a very non-threatening and appropriate respectful manner to the surgeon and then you would have to judge their response from there.

Mary: That's a great answer. I tell folks all the time, if you have a question like that related to your surgeon's specific numbers and volumes and outcomes as it relates to certain things. With any urologic surgery that we do, patients have a right to ask that and I think that Steve is right. If you get a dodgeball answer or hesitancy then that might be a flag that you may want to be getting a second opinion. The vast majority of the surgeons who I've worked with are very direct and straightforward with folks because at the end of the day it's the patient's life and it's the patient's body and we want everyone to feel comfortable with their treatment team.

Question 3: This question is from a patient who says, "My urologist is always too busy to answer questions during tests. How can I get information from him or it could be a her in some cases?"

Dr. Riggs: I think that's a very insightful question and I would say the reality of it is that all providers are experiencing this increased patient volume and challenges in how they manage their day especially in the clinic or in seeing patients. I can certainly appreciate that sense from some patients. I would say a couple of things. Number one, I think you have to understand and appreciate that there is going to be a time limit to that appointment. What I mean by that is if you take that approach and you come in there focused and ready and I guess to prepare i.e. you sit down and say to them i.e. you understand that you may not get 19 questions answered that particular visit, but you need to prioritize the three you want and make sure you get those three.

You have to help your physician or provider focus to you and the questions you want to answer, number one. Number two is I think if you figure the way they like to communicate, I think most providers will tell

you they're not as pressured in an email or electronic communication setting. If you say, "Hey do you mind? I know your time's busy and I know you have a lot going on, a lot of other patients to see, do you mind if I follow up with you with a couple of questions?" Then the third thing I would suggest is you didn't get it the first time, call back and say, "Hey, I would like to make another appointment." Then you just again, come in there with the two or three questions that you want.

Again, be realistic but also don't be unrealistic that you're going to get 75 questions. I wish it wasn't always that case but I think that's the reality and I think you need to understand the playing field that you are on at the time. Mary I don't know how much you have on that.

Mary: I think that's great. It's really complicated because at the end of the day we all wish that we could spend an infinite amount of time with folks face to face addressing all the questions that we could, but prioritizing is really helpful and just one more point to that is that, ask your nurses. The clinics nurses or the nurse navigators, sometimes they're excellent conduits for filtering your questions to your physician or your MP or PA, but also a lot of times they can answer those questions. The more experienced they are, the more they become experts in the nuances of treating patients with bladder cancer. If they can't answer the question, then they can certainly filter it to your provider.

Dr. Riggs: That's actually a really good point too. I would say I think some people or some patients feel like their questions aren't being answered because they're not getting it from the physician, but you got to realize in a team approach for a lot of places, especially places that do a lot of this, your nurse practitioner or PA, your advanced care provider, your nurse may be able to answer that question in a very different way and it satisfies your needs and/or answers the seven or the 10 questions you have and that it helps you get the other three … It answers the other three questions, so maybe not so hyper focusing that only a physician, a patient and feel like they have to answer everything may help you globally get you to where you're trying to go.

Question 4: Do you use IBM Watson to suggest a specific treatment for a patient with non-muscle invasive bladder cancer along with or instead of BCG?

Dr. Riggs: I'm assuming that's a slightly a humorous question, but I'm not familiar with anything outside IBM Watson, outside of the commercial, so I guess the short answer would be no.

Question 5: How do you find out if genetic testing is available or necessary for grade three non-muscle invasive bladder cancer?

Dr. Riggs: Again, I can check that. I'm a little uncertain of the exact question. The genetic testing in bladder cancer right now is still a progress, in evolution, so I'm not sure specifically what they're asking for in terms of that. I would need some more clarification and probably need to take that offline.

Stephanie: Yeah. I think it was more, how do you find out if it's available or not?

Dr. Riggs: It's currently not available in that space. There is no commercially available genetic test specifically for what they're talking about right at this time. There are a few genetic tests. Looking at different … A couple different spaces, but the short answer right now there's nothing in that space available.

Stephanie: Right. I think for some patients they might have a genetic test if they participate in a clinical trial because it's looking for those genetic markers. Am I right?

Dr. Riggs: Yeah, correct. I think that's the other way to infer that question or answer that question is, you may have it as a companion to a trial but a lot of it is exploratory and using it in the compounds of the clinical trial or in the boundaries of a clinical trial to understand different goals of the trial and different tissue based markers, but specifically to use it ubiquitously hey I show up, I've got a grade three bladder cancer and I want to use genetic test to better predict like we're doing in prostate cancer to do it in breast cancer. Right now that's not prime time ready.

Question 6: Should someone with bladder cancer look for a urologist who is a bladder cancer specialist or will a general urologist be acceptable?

Mary: Yeah. Honestly we have really wonderful partnerships with a lot of our community urology type practices close to us around the state and in other states. I think that's the general feeling at most academic medical centers and we get a lot of our folks come in from community urologists who may refer patients first who have blood in their urine and then did their cystectomy and did their tumor resection and then refer to us for just session of treatment options, because we are a bladder cancer center of excellence and have many specialists who are experts. Sometimes the way that it works is we will resume care of patients and once we're completed their access treatment with us, then they follow up locally with their local urologists.

It's a team approach. Sometimes patients will come to us from local urology to get a second opinion about should I do BCG and we check off and say, "Yes, we would do this too," and then they go back and they do their treatment there. Sometimes they go back and do treatments with local medical oncologists. I think what's really important between community urology providers, community medical oncologists and academic medical centers is collaboration and open lines of communication between the providers at each institution and also the patients. They know who's in charge of what aspect of their care. I don't know if Steve you want to elaborate on that.

Dr. Riggs: Yeah, it's a tough question. This is probably the question I get more than any question is does everyone with bladder cancer need to see a urologic oncologist or go to a center of excellence? I think the short answer is no. I think where it would take an hour to go through this, but I would say a couple of things. Number one is you should not be afraid to seek a second opinion. Sometimes all you're doing in the second opinion is just confirming that what you're getting done locally is okay in getting that level of comfort. Then … I think two you should pose that question to your urologist and I guess the other just logical thing I would say, "Listen, if you're in a really, really small area with one urologist who, two urologist and you've got a disease that is not … That they may not see all the time, it may be again worthwhile if you have the means to go somewhere else just to make sure that just to dot your Is and cross your Ts."

Also at the same time engage with that second opinion and hey can I not get this locally, can we not do this locally or come back at certain periods across the course of your treatment for a re-affirmation that everything's going the right way. At the same time there's a lot of good general urologists out there and they really know what they're doing in the space. I have a lot of confidence in our field that they do make the right decisions and that if they do feel like they need for you to go somewhere else for a second opinion, and hopefully they will be equally engaging you in that discussion.

BCAN would like to thank

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