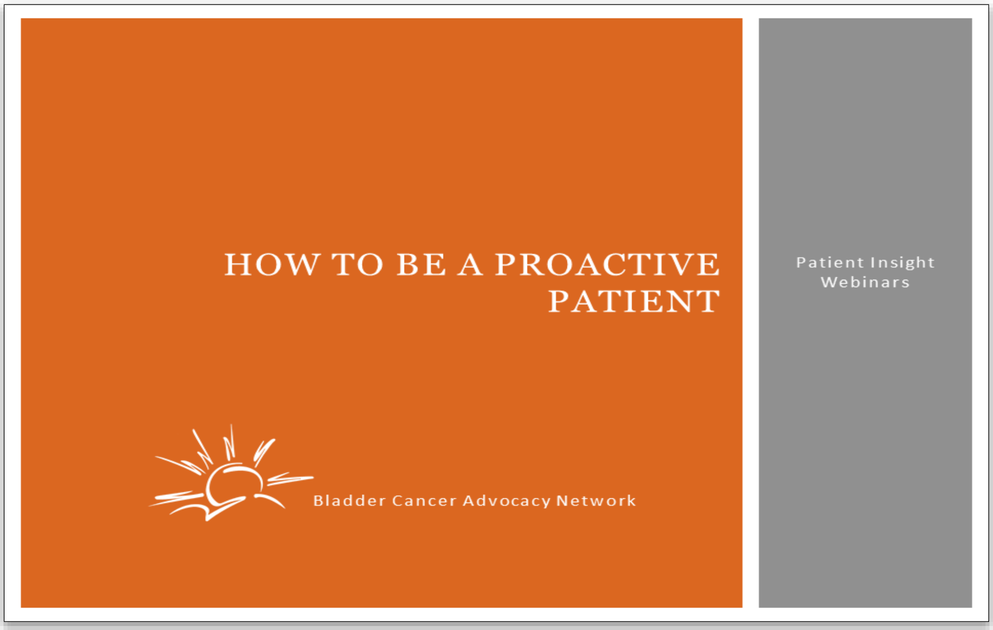

HOW TO BE A PROACTIVE PATIENT

Patient Insight Webinars

Bladder Cancer Advocacy Network

Stephanie Chisolm:

We've had a number of questions. Some of them are a little general, some are very specific. There was one comment from one of our advocates who's on here. He mentioned that MyChart powered by Epic has been instrumental in his bladder cancer case in subsequent surveillance and medical team communication for over 10 years.

And he was actually able to access all of his information when he was on a visit to a hospital in Dallas while on vacation. He wanted to know, "**In MyChart, do they (medical systems) talk to each other, these different medical chart systems so that if you're not in the MyChart system, you can get your information should you have to travel?**"

Mary Dunn:

Yeah, that's a great question. They didn't at first. And Steve, correct me if I'm wrong here, but all Epic-based institutions can see one another. It used to be, like when we transitioned to Epic years ago at UNC, that we couldn't see anything outside of Epic, which was a nightmare, because these electronic medical records are supposed to make things easier. We can see other systems outside of Epic now. I don't know which ones off the top of my head. But hoping that that's going to be something that continues to improve in the future because it makes care so much easier, not only from the provider standpoint but also from the patient standpoint, so things can be in one place. Thank you for the question.

Stephen Riggs:

Yeah.

Stephanie Chisolm:

Sure. Great. There's another question that two people have, so it's very similar. **What are your suggestions for older patients?** First of all, think about older patients might not be as comfortable questioning their doctors and speaking up for themselves because, oh, my doctor told me I needed to do this, so I guess I need to do this. So what are your recommendations for older patients themselves or for adult children of older patients who might be trying to intervene and be more proactive on their parents' behalf?

Stephen Riggs:

Yeah, that's an interesting question. Well, I guess the easiest answer would be to say, well, I think you shouldn't feel like that. And I'm not trying to make this simple. I just think you have to, again, understand that being thoughtful about what you want, thoughtful about and purposeful that you want to be engaged in your care. It's not necessarily questioning the physician, right? You're just trying to help your physician help you. That's the way I tell people to look at it. This is not questioning whether I know the answer or not. And I also think you flip that a little bit. I think that dynamic from the provider's side now, I guess that gap is older patients, younger providers. I don't think providers look at that, "Hey, you do everything I tell you." I think providers are looking for more of an engaged discussion as well and are very comfortable in the, "I don't have all the answers. I don't know everything. Help me help you."

I also think maybe one strategy is bring somebody younger. Bring your friend who might be younger or just your friend who might be more vocal. So not only bringing somebody but maybe bringing somebody and saying to them, "Hey, I'm traditionally uncomfortable in this space. Can you help? Can you be that personality that I'm looking for?"

Stephanie Chisolm:

So also in that population then you face some challenges with technology. You both pointed out some great resources. Obviously, BCAN has a lot of resources for patients and their families. **But what about some of the things that require them to interface with you through technology and they're clueless, what do you do then?**

Mary Dunn:

Paper.

Stephanie Chisolm:

Paper, the old-fashioned way.

Mary Dunn:

I miss documenting with pen and paper. I'm an old soul. So a lot of my patients who are older, and even younger patients who aren't tech-savvy or don't have access to technology, we always have to think about these access issues as well, will... We give folks, when they come into the cancer center, a generic cancer notebook. And then we put the BCAN stuff in it. And I tell them, if this is your preferred method of hanging on to information, keep this. Bring it with you to every visit. We can print off your lab results, we can print off your results. Just keep it organized that way. A big fan of paper, even though people yell at me for printing too much. Sorry, old soul.

Stephen Riggs:

Yeah. That's a great question. I think the number one thing I tell people is you need to be clear that... You don't want to write... It's like communication. The biggest problem with communication is the assumption that it's occurred. You don't want your physician and your physician's team who may favor internet, MyChart, right? Every EMR has a portal, email. If you don't do that, you need to be upfront.

That's a barrier. So number one, I'd say you need to recognize that barrier. For people who come a long distance who have no internet, you can only speak to them on the phone, so we do a lot by phone, phone visits, around that. I think also within that, you need to say, "Hey, the phone visit's not working for me. I need to come in."

I think sometimes as we feel easier in 2022 not coming in for a visit or doing it virtual or people like that, I think that works bidirectional. The physician has to try to understand when a phone or a virtual visit is not appropriate. And you need to say, "Timeout. I just can't get what I need out of this. I need to go in person." I think the other thing I like, what Mary said while there in her talk, is how do they like to communicate and how do you like to communicate? And most importantly, how do you communicate? Because a lot of times we don't even understand that till you tell us.

So we may not even be connecting because we think, oh, you didn't answer your email, et cetera. And you say, "Listen, I only have a home phone, and here's the number. Or who can I call after this appointment to get more information?" Because odds are, if you're going to be proactive, odds are there's no way in hell you figure it out in the first visit.

Stephanie Chisolm:

Yeah. Sometimes you just have to digest it all and just sit with it for a little bit. But then again, when you're given a diagnosis like cancer and bladder cancer, you don't feel like you have time to sit with it, so you just get really... I think many patients get a little excited, a little anxious at the same time. So here's another question that's come in. If a patient is geographically limited to be seen by a urologist and practice in a non-NCI-based urology clinic, what can they do to make sure that their doctor in their community... Because we know 70% to 80% of patients are being seen in their community, not at the large academic hospitals where you are. **How do we make sure that they get what they need to have in those community centers? What is your suggestion for them?**

Stephen Riggs:

Yeah. It's a hard question. It is. It's a great question. It's very thoughtful. We wrestle with this at the national level all the time. Now, that is not to say there's not great care going into the community because there is. And listen, I'm not here to ever say we should be bringing them all into some central area of care. I think what I would suggest is, A, there's a fair number of resources on the BCAN website to think about some word retrieval. And if you're uncomfortable, if it just doesn't feel right... I think I saw someone in the chat like, hey, they said there was no muscle in the... Or they didn't even mention muscle in the pathology. Well, just by the fact that that's ringing in your ear, and if you bring that up and you feel uncomfortable, you can certainly reach out to other places, not by traveling, but you can reach out and get consults from a distance. I have patients reach out to me all the time. And honestly, I ad-hoc look at their stuff and give them some feedback. And talking on the BCAN website though, looking for some resources on that, talking to patients on what they did. So not easy, but I think that's probably why I would say you need to be more proactive in that space if you feel uncomfortable.

Stephanie Chisolm:

Okay. Great. Thank you. And then the other question, there's just one other question I think. **How important is the role of the pathologist?** And when you're being proactive, with you all as primary providers there, the pathologist is not somebody that necessarily the patient sees on a regular basis or even knows much more about, other than the fact that they have this very big data sheet that says what their cytology is all about. **So how do you get proactive if you're not comfortable with what the pathologist's report is if you don't have any contact with that person?**

Stephen Riggs:

Go ahead, Mary.

Mary Dunn:

The role of a pathologist is crucial, especially when we're thinking in terms of a bladder cancer diagnosis, to distinguish between high-grade, low-grade, non-muscle-invasive, muscle-invasive. That could be a game changer. It's never a bad idea. In fact, we do this, patients request this from time to time, to get either a second read on the pathology from a different pathologist within the institution, or to have the pathology sent out to another institution of your choice. That can happen.

When we get new patients into UNC who have had their TURBT, so that's when we go in and scrape out the bladder tumor and look at it under the microscope, we'll request their pathology from wherever they had that done. And we'll read it at UNC. If you're ever wanting more information about your pathology report, there's definitely avenues to go down there. Steve, I don't know if you have any more thoughts there.

Stephen Riggs:

No. I love the question. It's a great answer. All right. So I'd say one thing. That's the easiest thing to get a second opinion without, quote, "leaving," right? Because you can say, "Sorry, here it is. Would you be okay sending my pathology for a second look?" Now you've empowered the physician. You've already let it out there. It's going to be very easy. If they ask you where to send it, well, you can look on the BCAN website, you can name just the closest academic center. Again, this is being a little bit prepared for that. I think that's important. Also, I will comment, it's a little bit near and dear to my heart. I've done a fair amount of research in this area. There's not an insignificant discrepancy rate between what one pathologist says and what the next says, assuming that the next is considered the expert. My point being that that's never a wrong answer.

Stephen Riggs:

And I would suggest, if I was in a rural setting, if I was in a small community, I think you should put that down in your box and ask for that. You don't have to go anywhere to do that. They send the slide, they send them back, you're checking the box there.

Stephanie Chisolm:

So the providers aren't going to feel a little insulted that they're being asked to do this again because I think that's part of the anxiety from a patient perspective of, "I don't want them to think badly about me. Maybe then they won't take good care of me." There's lots of things that go through people's minds. And that was certainly something that came in as a question. But it's not a bad thing asking for a second pathology read or anything like that.

Mary Dunn:

I think it's very kind and very generous when patients are concerned about how a question that they ask is going to affect me. At the end of the day, it's your life and it's your body. And we want you to be as comfortable as you can possibly be in this scenario. As long as you're not yelling at me and throwing things at me, that would hurt my feelings. But asking for a second opinion on a pathology read or a referral to another institution, those are things that are simply advocating for yourself and not at all... It shouldn't be insulting to your team.

Stephen Riggs:

Yeah. Stephanie, it's an interesting... I keep hearing that comment. I really appreciate it. I always think, as providers, I look at the way healthcare is delivered very differently than when it's being delivered to me. And what I would say back is that doesn't get on my radar, but I understand that happened. I think that is misinformation, unfortunately. And I'm sure... I'm not suggesting that that doesn't occur, but I think that is a misrepresentation of how physicians feel in general. I would feel very comfortable saying that most good physician-patient interactions occur bidirectional, receiving and giving, being engaged. It's much more easy engaging for me to be interacting with you because you'd be a little bit prepared and we can be a little bit thoughtful in discussing. That's a much easier intellectual interaction and I think a much more helpful interaction than, again, me just sitting back and accepting everything you say.

Again, to Mary's point, you're trying to help yourself out. You're trying to get the best care possible. Medical care is no different than life. Sometimes a squeaky wheel gets greased. Right? And you being active and in front of them and knowing that you're prepared often leads you down to the right place, the higher quality. So you want to assume that position in that interaction.

Stephanie Chisolm:

Right. So being proactive is not being aggressive or rude, it's standing up for yourself or for your loved one, right? Okay. Well, this has been phenomenal. This is a great resource. I'm very thrilled that we were able to update the content because this is just always such an important topic for patients.

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