



Understanding Bladder Cancer Pathology

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Part I: A Patient Centered Approach

Presented by



Dr. Matt Mossanen went to college at the Medical School at UCLA. He completed his residency at the University of Washington in Seattle. He committed a year of his training to research. He's now a fellow at the Harvard Combined Program in Urologic Oncology at Brigham Women's Hospital and Mass General Hospital in Boston. His research interest includes patient-centered approaches to bladder cancer care and this last summer, Dr. Mossanen was one of our travel fellows at the BCAN Think Tank Meeting in Denver, Colorado.

Welcome again to Understanding Bladder Cancer Pathology, A Patient Insight Webinar from the Bladder Cancer Advocacy Network. We're very excited to have Dr. Donna Hansel and Dr. Matthew Mossanen joining us tonight to really talk about a really confusing issue for bladder cancer patients.

A blue rectangular slide with white text and logos. The text includes the title "Understanding bladder cancer pathology", contact information for Dr. Matthew Mossanen, MD, and his affiliations. Logos for the University of Washington, MGH, and BWH are shown at the bottom. The BCAN logo is also present in the center-right.

Understanding bladder cancer pathology

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Great. All right. Good afternoon and good evening, everyone. I'm very excited to be here today. I want to start off by thanking Stephanie and especially BCAN for inviting me to speak at this webinar. Bladder cancer research is really one of my passions and I consider it an honor to have a chance to share a little bit about my own research in bladder cancer pathology. During my residency, I was lucky enough to work with Dr. Gore and do some research looking at patient-centered approaches to bladder cancer care and specifically looking pathology reports.

In this webinar along with the expertise of Dr. Hansel who's the pathologist, I hope to tackle a few questions during this webinar. The first one is to talk a little bit about patients understanding of their pathology report perhaps, some of the barriers that patients face when they're trying to understand their diagnosis. Another topic to focus on, what do experts think are some of the most important elements that a patients should walk away with when they're trying to understand the information in the pathology report.

Lastly, I want to touch a little bit about on my own work that deals with how we can design and pilot test patient-centered resources for individuals with bladder cancer specifically looking at a patient-centered pathology report for people that have bladder cancer. Before we started out on this work, one of the things that we were most interested in was looking at the literature and scouring it for sources of information that patients can use when they're trying to understand the pathology report. We get a literature and we'd be looking at the most common cancers on men and women and try to find themes and also find what resources are available.

Patient Centered approaches to bladder cancer care

- What do patients understand about their pathology report?
- What do experts want the report to convey?
- Can we design a patient-centered pathology report?

The diagram illustrates the anatomy of the bladder and surrounding structures. Labels include: Bladder, Ureter, Fat around the bladder, Muscle layers, Connective tissue, Inner lining, Cancer, Prostate, and Urethra. The cancer is shown as a mass within the bladder wall.

Now, as you might suspect, breast cancer and prostate cancer had the most resources. Bladder cancer actually had very few. Some of the other things that we found in our work are that there's a current effort underway to standardize pathology reports, so that they all have the same contents and organizations. Still, a class different institution, different documents are often generated. One of the important points here is that pathology reports are really a communication document for doctors. It's a way for the pathologists to give information to the doctor about not only cancer stage but also about prognosis and about treatment options.

Patient Centered approaches to bladder cancer care

- Readability of pathology reports
 - Patients should be able to read and understand the report so they are better informed of their diagnosis
 - A cancer diagnosis is a scary event and figuring out options can be confusing
 - This information guides treatment decisions

A yellow awareness ribbon is positioned to the right of the text.

Moving on to the next slide, we decided to think a little bit more about how we could focus on specific pathology reports not just looking at the overall content out there on the internet or in the research literature but focusing on our own pathology reports at our institution at the University of Washington. One thing we were interested in was the readability of pathology reports, which means that how accessible is this document. Now, in my opinion and according to BCAN, we all believe that patients should be able to unders

tand the pathology report, so that they can grasp their diagnosis.

Quite honestly, a new diagnosis is scary. The information and the document is complex and trying to navigate this balance for patients can be very difficult. Even though this is a daunting task, it's essential that patients have access to information that can help them make sense of their bladder cancer

diagnosis. What we decided to do was to study the complexity of the words and the sentences in a pathology report for bladder cancer. What we found, as expected is that these are complex documents. They're written with medical vocabulary that's not used in the average conversation.

A little bit later on this talk, Dr. Hansel is going to talk about what that's essential that these documents actually do entail some degree of complexity. In our work, we tried an experiment. We thought, let's try to make this more accessible for patients. What if we just delete some words or substitute some words and see if that makes it easier to understand. What we found was that simply removing words and putting in simpler ones doesn't necessarily make this document easier to read. In my opinion, the finding by itself shows how important it really is for patients to understand their pathology report.

Readability of Pathology Reports

What did we learn by studying pathology reports in bladder cancer?

- They are **complex** documents!
- Deleting terms and/or substituting terms does **not** always make it easier to read.
- Highlights the importance of **asking questions** from the urologist, pathologist, and/or medical oncologist.

Mossanen et al. Urologic Oncology; March 2014

One of the best ways to do that, I think, is by asking questions and this is something that I'll highlight again later on in the talk. For patients that are facing a diagnosis, it's very useful to ask questions from the pathologist, the urologist, the medical oncologist, or even the radiation oncologist. The other important takeaway point from this work is that we found that if we wanted to create documents or patient-centered resources that are useful for patients facing a diagnosis of bladder cancer, it was going to take a more patient-centered approach.

Realizing that this was a complex task, we decided to survey a panel of clinical experts. We asked pathologists, radiation oncologists, medical oncologists, researchers, and of course urologists from throughout Washington State and the country what they thought the most important elements of a pathology report were. We gave them several options but at the end of two rounds of survey, the experts felt like stage, grade and histology were the most important elements of the pathology report.

Asking the patient advisory board

- When asked, this is what patients wanted to know from the report:
 - Narrative format
 - Using a Question and Answer style
 - Picture
 - An illustration of the bladder wall the tumor in it
 - Recurrence risk
 - What are the "chances" it will come back?

Fortunately, later on tonight, Dr. Hansel is going to touch on some of these in more detail. After we were able to get this information, we then decided to turn our attention over to a patient advisory board. What we decided to do is to focus on patients with an actual diagnosis of bladder cancer. We did a focus group and we talked to them. We said, "What do you think is important in a pathology report? What do you want to know about your diagnosis?" The three most important things that came out of it are listed here in this slide.

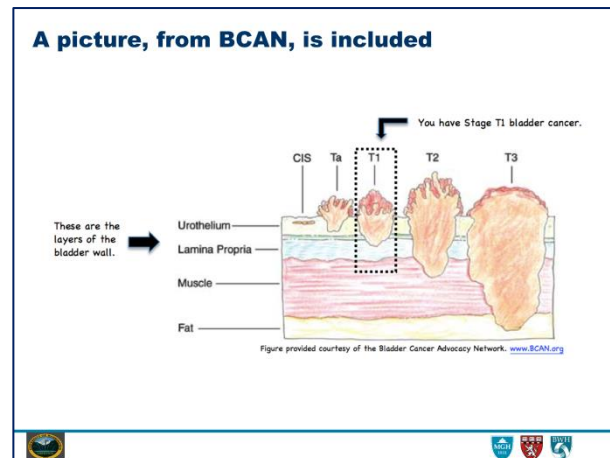
The first one is that they wanted a narrative format. What does that mean? That means that if somebody were reading a document about their cancer diagnosis, they wanted to have a question and

answer style. They want to feel like they're sitting down and having an informal conversation with his friend. The next thing that we were able to elicit from the patients we talked to was that a picture is a very valuable way to illustrate the concept of tumor stage. We decided to include an illustration of the bladder wall as a way for patients to understand their diagnosis. In the next slide, I'll show an example of that.

The last theme that came up time and time again from many of the patients are that they want to know based on the information in the pathology report, "Doc, what are my chances that this chances will come back?" Taking the information that we had from our expert panel and then, our patient focus group, we decided to put all of that together and created a patient-centered pathology report that's shown here on the right side of the slide. It's important to mention a few things about this example. One, this is a tool. This is not meant to replace the pathology report that has a very important place in medical care for anyone with cancer.

One of my hope is that this sort of resource, something that is patient-centered and patient-friendly can be added to the standard report to help patients understand their diagnosis and be empowered to ask questions, even questions perhaps in the pathology report that's listed here, so that they can begin to feel like they had a better grasp of their diagnosis. I think ideally down the road, maybe an approach where we have patient-centered resources and the standard resources is a nice way to combine medical resources to improve patient understanding of their diagnosis and therefore, their ability to select the proper treatment.

Now, one of the most popular features of the pathology report is that it has a customized figure and this is our patient-centered version. We actually borrowed this picture courtesy of BCAN. What you see is that we highlight with a dotted rectangle the stage of bladder cancer and very clearly point out the layers of the bladder wall. This helps patients understand the depth of their tumor growth and therefore, the stage of their cancer. I still remember the first time I showed one of these illustrations to a patient who had never seen a cartoon of the layers of the bladder. I remember his face when he had the "a-ha" moment of what a tumor stage actually represents.



We decided to take this document and do a small research study at our institution at the University of Washington and we found that patients that received the patient-centered pathology report along with the standard report did a better job of actually reporting their cancer stage. While this is just a pilot study in a small group of patients at just one institution, I find it hard to understand how a more well-informed patient can be a bad thing. What I think this project starts to hint at is that if we give patients the opportunity to access more patient-centered resources about their disease, they can take advantage

of it and become more well-informed about their diagnosis.

Now, a few takeaway points. I think it's really clear based on some of the research we've done not only looking at the literature as a whole but focusing on pathology reports, these are complex documents and Dr. Hansel is going to touch on exactly why that is a necessary thing in oncology. They contain important information but sometimes, they're not straightforward, so it's difficult for patient to understand. A second takeaway point is that patient-centered health resources can really help us not only improve patient understanding of the disease but also help guide them in making management choices.

It's my hope that as we move forward in the future, we can create more of these sort of documents for patients, so they can sort through the sea of information that they often face during their cancer care. Third, and perhaps most importantly, when I doubt, I want to encourage patients to ask questions about their pathology. They should take advantage of people involved in their care and their field of expertise. Urologists are available. Many pathologists such as Dr. Hansel will sit down with their patients and have discussions about their pathology. Medical oncologists, radiation oncologists are all available.

Take Away Points

- Pathology reports are **complex documents**
- **Patient-centered** health resources can help improve patient understanding
- Patients should be willing to **ask questions** about their pathology report
 - Urologists
 - Pathologists
 - Medical Oncologists

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Other tips are to take time to review resources that are out there much like some of the wonderful things offered on the BCAN website and another suggestion is to get involved. In the future, a lot of bladder cancer research is actually going to ask patients what area do they think are important to focus on. I give a lot of credit to some of the works done by Angie Smith at UNC and John Gore at the University of Washington that are designing a research tool in, which we survey patients and ask them what we should focus on as we look to design research projects in the future.

I'm also happy to say that we're slowly moving forward with a multi-centered file of looking at bladder cancer patient-centered pathology reports to see its impact on patient understanding. Lastly, I want to thank all of the patients that gave their input and shared their experiences to help us at this work. I want to thank BCAN and Stephanie for this wonderful opportunity. Also, Dr. Gore for his mentorship and for being the mastermind behind this project. In closing, I hope that this webinar has been useful for many of you facing a diagnosis of bladder cancer and I want you all to know that you're not alone and I thank all of you for your time. Thank you very much.

BCAN would like to thank

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