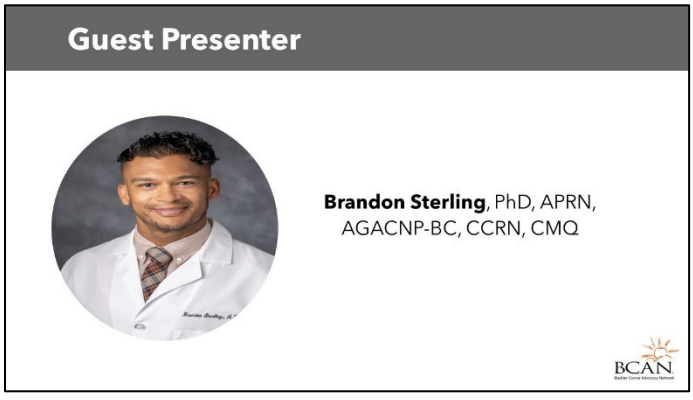
Part 1: How can caregivers help when their loved one needs bladder removal?

Patricia Rios:

Welcome to the Bladder Cancer Advocacy Network Patient Insight webinar series. I am Patricia Rios, senior education and advocacy manager and your host for today's webinar. Today's topic is how can caregivers help when their loved one needs bladder removal?

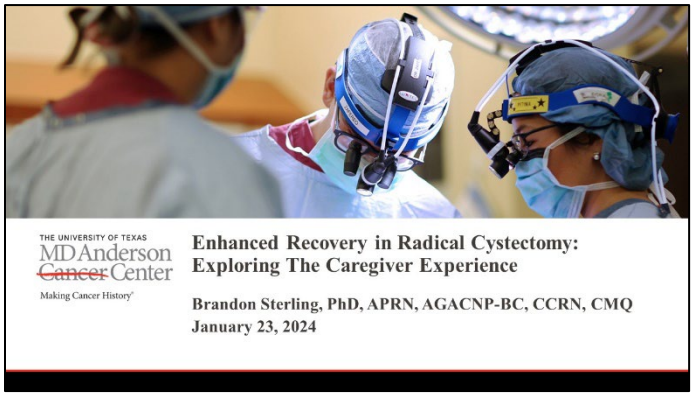


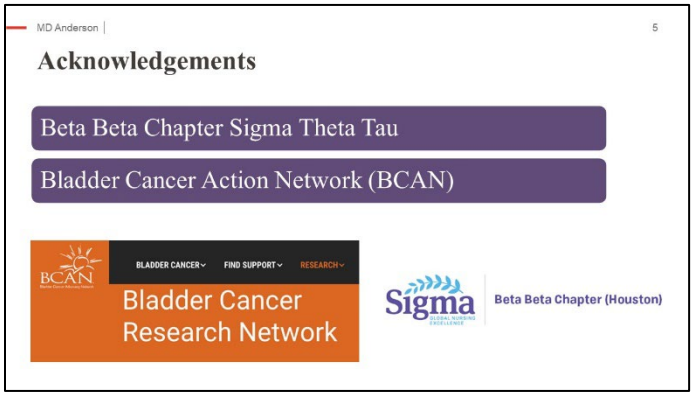
I am delighted to introduce you to our guest speaker for today, Brandon Sterling. Brandon is an advanced practice provider navigator at the University of Texas MD Anderson Cancer Center and an assistant clinical professor of nursing at the University of Texas Houston Cizik School of Nursing. He completed his PhD of nursing at Texas Women's University and has a research interest in caregivers and bladder cancer patient related outcomes. Brandon uses whatever spare time he has to help advance BCAN's mission of increasing public awareness about bladder cancer, advancing bladder cancer research and providing education support services for the bladder cancer community by volunteering his time and expertise to serve on BCAN's survivorship task force, as well as being a guest presenter.

Today Brandon is going to introduce us to enhanced recovery programs and how they're used to improve the health outcomes of patients in need of cystectomies or bladder removal. Most importantly, he will explain the realities and experiences of cystectomy caregivers during each phase of the enhanced recovery program based on research. He will conclude by giving us insight into how patients and caregivers can be active and engage members of the healthcare team during the cystectomy journey. So without further ado, I'm going to hand it over to Brandon to begin his presentation.

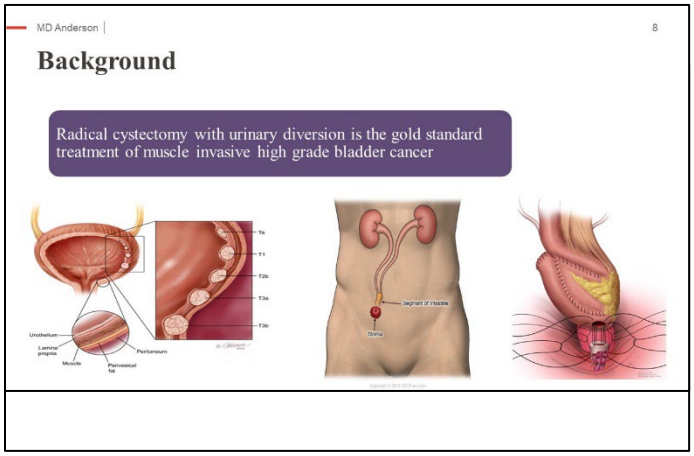
Brandon Sterling:

Again, I wanted to introduce myself again. My name is Brandon Sterling. I'm an advanced practice provider navigator at the University of Texas MD Anderson Cancer Center. And I've been tasked today with reviewing enhanced recovery programs, as well as going through the caregiver perspective within the context of enhanced recovery programs. And the cool thing is I actually did my dissertation research study on this, so I'm very passionate about it and I was telling Patricia and Stephanie even before we logged onto the meeting, I now have a very personal connection with being a caregiver, having had my own personal experience this past year, and most recently I've been a patient, so I've had the best of both worlds.



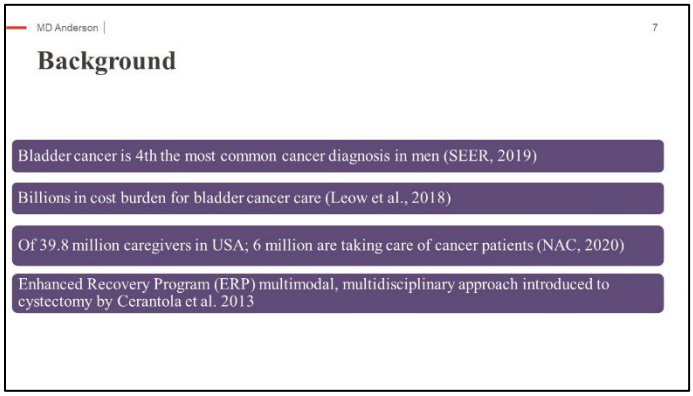


So I can relate on a certain level, but just having to depend on others, that's just a whole new experience. So I'm happy to be here to go through my research and also really touch on enhanced recovery programs. So I want to first acknowledge the Beta Beta Sigma chapter of the Sigma Theta Tau, which is the nursing organization that helped to support my research as well as the Bladder Cancer Action Network- Advocacy Network, I really thank you guys for supporting me in my research efforts and helping to basically set this platform for more opportunities for research.



Brandon Sterling:

So again, what I'm going to do is briefly go over the background of bladder cancer, do an overview of enhanced recovery, and then really dive into the research findings in the caregiver integration. And then finally at the end, we will reserve some time for you all to ask your questions and I will answer them.



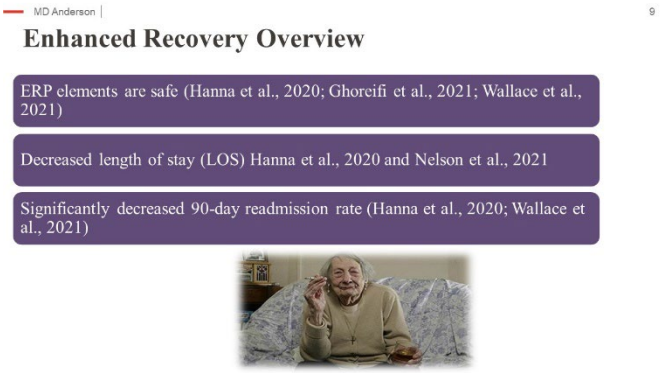
So of course bladder cancer is the fourth most common cancer diagnosis in men. Billions and billions of dollars is spent when it comes to bladder cancer and there's actually quite a cost burden given the, excuse me, trajectory of care from initial cancer diagnosis to let's say survivorship, billions of dollars is spent. And then one interesting factoid is of the 39.8 million caregivers in the US, 6 million of those caregivers are taking care of cancer care patients and of course enhanced recovery. If you haven't heard it before, do not fret because what I learned actually in my research study that many surgery teams are more explicit, some are more explicit in describing enhanced recovery than others.

So if you haven't heard about enhanced recovery before and you're like, "Man, did I encounter that during my surgical procedure? Or is this something that I can ask about while I'm doing my surgery planning for my loved one?" May this be a resource to you because again, one thing that I learned very early in my research study is that a lot of the surgery teams do not explicitly say enhanced recovery, but they do include each element within their practice. So we'll get all of that.

So of course, radical cystectomy with urinary diversion is the gold standard treatment of muscle invasive high grade bladder cancer. So usually if you get the big diagnosis and you hear the word high grade and or muscle invasive, then typically the next question is when can we schedule you for surgery? And I'm a visual learner, so I included different photos here just so you can see the anatomy of the bladder. And when we say muscle invasive, that means it's going through the urothelium into the lamina propria into the muscle.

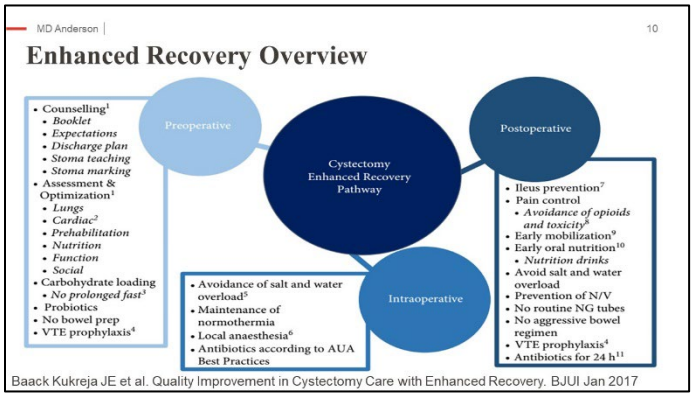
Brandon Sterling:

And then I also included a couple pictures of different diversions. I could not fit the picture of the Indiana pouch, but do not fret. I did think about Indiana pouches while I was making this presentation, but we do have a picture of an ileal conduit as well as the making of a neobladder here.



Now, as far as the overview of enhanced recovery, I wanted to really highlight that many of the elements have been researched and shown to be effective, and it's also been shown to decrease length of stay in the hospital and then also significantly decreased the 90-day readmission rate within radical cystectomy. And this picture of this lady here, I love it because it encompasses of the typical bladder cancer patient you will see. As you can see, she's enjoying her cigarette and she's an older lady, so bladder cancer is typically a cancer of the elderly population and those who have a strong smoking history. So I guess you could say that's our mascot for bladder cancer.

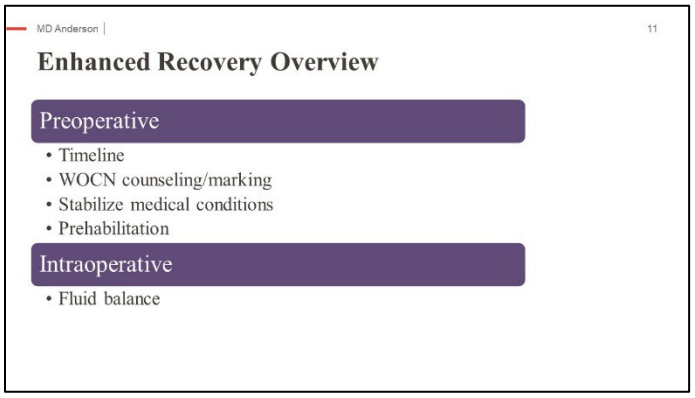
Brandon Sterling:



Now, this slide here is busy, but the reason why I wanted to use it just to give you a general overview of the enhanced recovery program in all of its elements, and some call it the enhanced recovery pathway, some call it the enhanced recovery journey. So depending on the nomenclature that your practice uses or the practice where you're getting your care uses, this is pretty much it. There's a preoperative phase, an intraoperative phase as well as a postoperative phase. So the intraoperative phase, there's minimal integration of caregivers in the intraoperative phase because they're actually in the operating room. So the focus of that is mainly for the anesthesia teams. And again, I will touch on that.

So I will say probably the hallmark or foundational period for enhanced recovery is the preoperative period because this is when you are talking to the team about timelines you are going for your initial visit to the wound ostomy care nurse or the wound ostomy care professional for your initial counseling and marking.

Brandon Sterling:



And that counseling can include, this is the urinary diversion I've chosen and this is how you're going to care for it after surgery. Now, it's really challenging because you get this tsunami of information, but if you're anything like me and you're a very hands-on person, it's very hard to teach me something when I don't have the actual material. So many patients have told me it's very challenging to go to that pre-op visit and learn how to change the stoma, but I don't have a real stoma to change it on. So that's when postoperative, all of the real fun begins. And then also one thing that we really focus on in the preoperative period is to stabilize medical conditions. So if you're smoking, you stop smoking. If you're a diabetic, do we need to reach out to our colleagues to help control your diabetes?

And then of course, prehabilitation. And when I explain prehabilitation, some people are like, "Well, now do I need to go to the gym and start doing pushups?" And the answer to that question is absolutely no. So it could be a matter of just you walking to the mailbox or meeting with a physical therapist before surgery or a physical rehab specialist just to discuss some type of increase in physical activity before surgery. And what it does, it lays a foundation of what you can do after surgery. So again, this is a foundational period. This is when you select your... Well hopefully after you've selected your diversion, this is when you get into the nitty-gritty. But research has shown, and per my experience, a lot of this information tends to go in one ear and out the other. But if you're in a very excellent practice, then what we like to do is provide our patients with multiple media as far as how they can access the information, whether if it's a piece of paper, or a packet, or online videos.

And of course, we always direct our patients to go to the BCAN website for resources as well because there is a plethora of different videos and testimonials. And if you haven't heard about it yet, of course, the Inspire platforms. So where you can pick the brains of other experienced caregivers or patients who've had the surgeries before. Because in my personal experience, I can always explain these things to a patient or a caregiver, but sometimes the best resource is someone who's already been through it. And that was an ongoing thing throughout my interviews when I did my research, so we'll touch on that a little later.

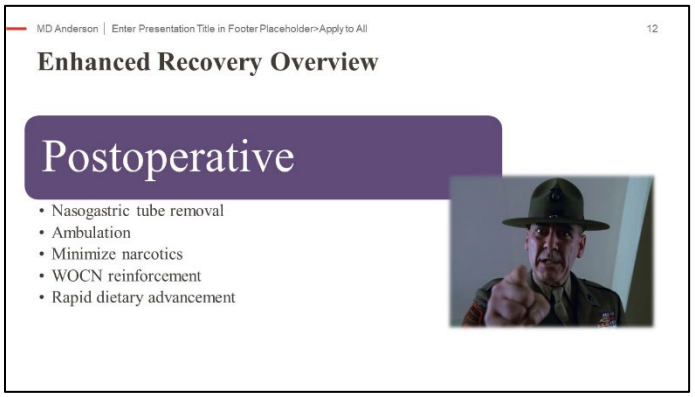
And then of course, one major element to the enhanced recovery again is intraoperative. And basically like I said, there's little to know interaction with the caregivers during this period of time because you'll be in the operating room, your loved one will be in the operating room. So mainly it's about keeping a normal temperature. It's about maintaining a fluid balance because research has shown that back in the day when they used to pump patients full of fluid in the operating room, it used to cause a wide range of postoperative complications and one of the major ones being atrial fibrillation.

So, if you think about it, once you're fluid overloaded, then your baroreceptors go out of whack. And then it's not uncommon, especially in patients with advanced age to go into these heart arrhythmias. So

once they discovered that, "Hey, maybe we can be a little bit more conservative with the fluids." Then they notice that the rate of atrial fibrillation, postoperative fibrillation decreased.

Brandon Sterling:

And then here is where I usually would come in when I worked inpatient is the postoperative phase. And if you see, I have this photo of this drill sergeant here because it was actually a team or a dream team of myself and the caregiver or their loved ones who turned into this drill sergeant because one of the tenets of enhanced recovery in the postoperative phase is movement, my getting you out of bed.



And then a lot of patients would be like, "Well, I have all these drains and tubes, so how am I going to do this?" So that's when we would team up with nursing and PTOT and you would have a little ornamental gown where we would pin everything to your gown and make sure that we did whatever needed to be done to get you up and moving. And a lot of folks would be like, "Oh, I want to walk around two or three times." And I'd like, "No, let's try it for five or six." Now, although we wanted to minimize narcotics, what we would typically do is start you on a non-narcotic regimen, which was scheduled, meaning that you didn't have to ask for these pain medications because we would give it to you regularly. So in the event that the physical therapist just showed up randomly out of the blue, you would be ready because your pain would already be covered by those scheduled medications.

And when I say non-narcotics, it would either be intravenous Tylenol or oral Tylenol, Celebrex or some other non-narcotic pain medicine. And I think the strongest we would give for a narcotic at MD Anderson was tramadol, unless you had some really bad breakthrough pain. But I would always like to tell my patients, "This is an absolute." Because ultimately for you to progress and heal, we needed to have your pain under control. And depending on different circumstances, if you had chronic pain or other aggravating factors, which cause your pain to be worse, it's not like we refuse narcotics, but we was trying to minimize it. And I just wanted to say that every patient is different, but ultimately that was the goal. But being in healthcare, one thing that I've learned, there are no absolutes. So we would try our best to minimize narcotics, but if you needed that extra dose of a narcotic just to get you up and walking and to reach those discharge milestones, then that's what we would do 100%.

And then this is also when the wound care nurses or the wound care professionals would come in and do the diversion teaching. At MD Anderson the wound care nurses would have, you had a three-round rule with them. On the first two rounds, they would come and change the stoma. They would teach you hands-on literally with the stoma on the patient on how to change the wafer on the ileal conduit or do the flushing with the neobladder. And then that third round would be for you to do it yourself, the caregiver. So it was like you could not graduate and discharge without you showing the wound care nurse that you were capable of changing that pouch. And I will also add, at MD Anderson, we are very resource rich in the fact that our wound care department, it's an entire department, meaning that they have their own outpatient clinics.

So our patients who needed an extra lesson, if you will, post discharge, then they would just schedule an appointment with the wound care specialists in their clinic maybe a week or maybe in a few days after discharge for them to follow up. And then one thing that I always would make sure my patients who are out of town, that we could find some type of home health agency that had a wound care nurse on staff or had somebody with knowledge of wound care and stoma care to come to their home and maybe do that follow up care. And then with the pandemic, of course, they were even able to offer video visits to patients. And you have this new thing that you're doing, so sometimes it would just be the fact that, "I just want someone to watch me. I think I got it down, but I just want someone to watch me." And they were able to offer those services even throughout the pandemic.

Brandon Sterling:

And then one more element of the enhanced recovery is the rapid dietary advancement. So this would vary depending on the surgeon. You would have the younger surgeons, they'll be like, "Oh yeah, just start them on a regular diet post-op day one." Whereas some of the more senior surgeons were like, "Okay, let's do a stepwise approach to this and do the clear liquids and the more traditional advancement of the diet." But one thing I had to learn living in Texas, and I think you all will appreciate this, I would have to tell my patients, "Your first meal after surgery on post-op day one should not be a cheeseburger with fries." Or, "No, you cannot have that barbecue brisket brought in from Pappas Bar-B-Q to have as your first meal after surgery." So I would always tell them, "Let's keep it maybe some toast and crackers just to start out."

But again, being in Texas, you'd be surprised at... I will walk in and see this tray, it's like a mini buffet of food. And I would warn them, "We want to encourage you to do some food intake. However, this is not the way to go with the cheeseburger and fries on post-op day one." But what does happen, and it's just part of the surgery, because remember with the creation of the diversion, there's manipulation of the bowel. There's actually a decrease of appetite. So a lot of patients would tell me initially after surgery, even on follow-up telephone calls after discharge, "I don't have an appetite. I don't have an appetite." And that's an absolute normal finding.

So that's when, again, we would reinforce the protein shakes and just sip on those all throughout the day because essentially you will need some type of protein to help facilitate healing. So it's just one of those things where I'll go back to my picture of this drill sergeant here, is like, "It's really important that you intake those calories, whether it be through liquid or the small frequent meals, but you must increase your protein intake and supplement if needed."