

Part 2: How can caregivers help when their loved one needs bladder removal?



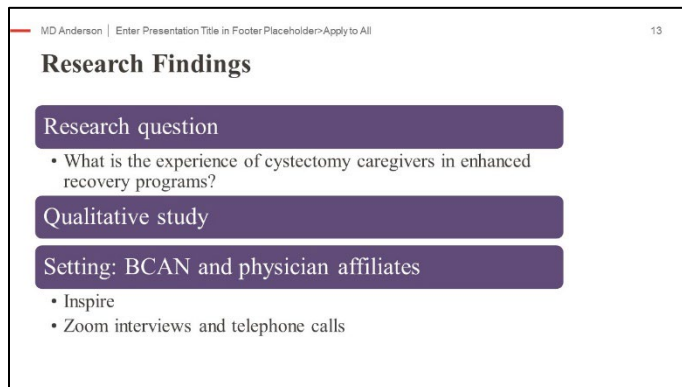
Patient Insight Webinar Series

Enhanced Recovery in Radical Cystectomy: Exploring The Caregiver Experience

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Brandon Sterling:



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Research Findings

- Research question
 - What is the experience of cystectomy caregivers in enhanced recovery programs?
- Qualitative study
- Setting: BCAN and physician affiliates
 - Inspire
 - Zoom interviews and telephone calls

So, I will now segue into my research findings.

So the whole premise or the whole way that I came about to this study was I would take care of these patients post-surgery and then I would look in the research and I was like, "Huh. One of the cornerstones is missing from all of the literature out there regarding the enhanced recovery." And that's the perspective of the caregivers because

ultimately nothing in the home works as far as care goes without the input of the caregiver. For example, if we tell you "you need to go to your prehabilitation appointment" or we're teaching you about the nutrition shakes and you need to do this and do that, well, who's going to do all that while you're recovering from surgery? It's going to be the caregiver.

So I was like, "Man, this is a great opportunity for me to explore these perspectives and then publish it and give the caregivers a voice in all of this." And that's what inspired me to do this study. And I'm very much an advocate for nursing research and especially nurse practitioner or advanced practice provider research because we have this unique perspective where we have a foot in the door with medicine, and then we also have a foot in the door with I would say basically the front lines in nursing. So it's just one of those things where I was like, "Caregivers are so important, and for you to have a program that's so

structured and so regimented and follow up appointments and teachings and things, how can you be successful without the input of the caregivers?" So that is what led me to my research question, which is what is the experience of cystectomy caregivers in enhanced recovery programs?

So I ended up doing a qualitative study, and the way that I ended up getting connected with BCAN is through the chair of my department. He emailed Stephanie and then Stephanie emailed me back, and then I was provided a letter and then we moved forward. So with the qualitative study, I ended up doing a lot of Zoom and telephone interviews. And the reason why is I was doing all of this during the height of the pandemic, believe it or not. And then also my role is different, I was actually working in the ICU before I transitioned back into urology, so if you can imagine the amount of stress it was. But I thought about how the caregivers and the patients persevere through this time, I can do this too, as far as giving them a voice and help in doing this research study. So I work with BCAN and it's physician affiliates to help and recruit for the study. So we recruited through Inspire, and then just sometimes it was just through word of mouth to get the word out on this study.

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Research Findings: Themes

- Partnership and Feeling Connected
- Elements of Resilience
- Seeking and Accepting Knowledge
- Transitional Recovery Thresholds

So as far as the themes go, the themes that I found throughout my study is the four major themes were partnership and feeling connected, elements of resilience, seeking and accepting knowledge, and transitional recovery thresholds.

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Research Findings: Themes and Subthemes

Partnership and Feeling Connected

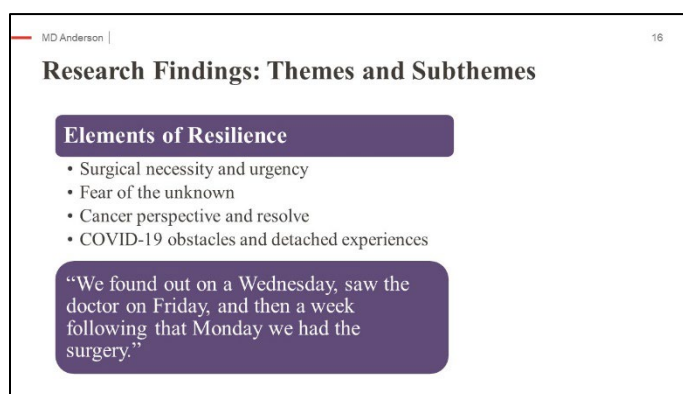
- Family and Friend support
- Medical/Nursing support
- Vigilance and devotion

"It's a partnership, and you, and the patient, need to bring forth your questions, your determination, your dedication, your belief you are going to get well."

So partnership and feeling connected. So many of the caregivers had mentioned that, especially throughout the pandemic, they relied on different networks of support to help them throughout the process. And this could be friend and family support, church group support, even other caregivers and other patients that they would link up through either Facebook groups or BCANs' Inspire program, and then also medical nursing support. So I will say it varied quite a

bit throughout the nation depending on where you were located, because some had revealed we really needed that wound ostomy nurse locally because we're in a rural community in Wyoming and there was no wound care ostomy professional within 100 miles of us, so we had to make do and make those two hour trips.

And then as far as the vigilance and devotion, man, the caregivers were just a steadfast and just supportive of their loved ones. I have a quote here where one of the caregivers said, "It's a partnership and you and the patient need to bring forth your questions, your determination, your dedication, your belief that you are going to do well." So a lot of the caregivers were like, "Well, no one really wanted to have surgery during the pandemic because there are limitation on visitation." So everybody was scared. But then the next question was, "Well, what is the alternative? What do we do if we don't have the surgery?" And nobody wanted to even consider the alternative, so they all move forward. So through the power of different social networks, whether it be virtual or in-person, many of the caregivers felt like they needed that strong support system, especially in the setting of the pandemic.



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Research Findings: Themes and Subthemes

Elements of Resilience

- Surgical necessity and urgency
- Fear of the unknown
- Cancer perspective and resolve
- COVID-19 obstacles and detached experiences

"We found out on a Wednesday, saw the doctor on Friday, and then a week following that Monday we had the surgery."

And as far as the next theme, the sub themes for the elements of resilience were the surgical necessity and urgency, fear of the unknown cancer perspective and resolve, and then COVID-19 obstacles and detached experiences. So I didn't want to make one of the major themes, COVID-19, because it was just one aspect of the different elements of enhanced recovery or looking at the different experiences of the

caregivers through enhanced recovery. But as far as the surgical and necessity and urgency, a lot of the patients or their caregivers were like, "Well, we were really impressed by the enhanced recovery program and everything that was brought to it. However, we did the initial resection or the TURBT on Tuesday, and we were back in the office on Friday, and then we were scheduled for surgery that next Wednesday." And that's how fast everything went.

So a lot of the caregivers were like, "Yes, the preoperative phase was great, and they had wonderful plans, however, everything just happened so quickly." So that's when they reinforced those resources, having the packets or having the BCAN website as a resource for them to go back. Because I don't know how many out there have had this experience, but a lot of the patients tell me, "Before surgery, it's just a blur. You just hear the diagnosis and then you know you kind of go blank." And then the next thought is, "Well, how do we get this done? How do we get the surgery?" And then depending on the situation, some people were in surgery, their loved ones were in surgery that next week. And then of course there was a fear of the unknown. And I think, well, a lot of the caregivers expressed that they were relieved to have the surgery and relieved to hear that the margins were negative, but then it was that four to six wait for the final pathology to be reported to them along with this new thing they had to do at home with the different diversion care.

So there was a lot of fear, but the way that they would cope with it ties into the next sub-theme, which was cancer perspective and resolve. And many of them were like, "Yeah, we were scared. However, given the alternatives, we just didn't want to think about that. So we just have to move forward and press on and depend on our resources and access our resources." And as far as the COVID-19 obstacles and the attached experiences, a lot of those appointments were limited to maybe one person, and that could

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Research Findings: Themes and Subthemes

Seeking and Accepting Knowledge

- Self-initiated education
- Surgery team education
- Diversion education

“We read lots of material. Of course, we talked with physicians, nurses and they explained it. Of course, internet research, we were just looking.”

just be the patient. So the caregiver had to either FaceTime in or Zoom in to really get the full breadth of the information. And then unfortunately, just given the circumstances during the pandemic, a lot of them reported, "Well, I couldn't even wait in a waiting room during my loved one surgery, so the surgeon called me while I was sitting in the parking lot on the phone with family members waiting for an update."

Brandon Sterling:

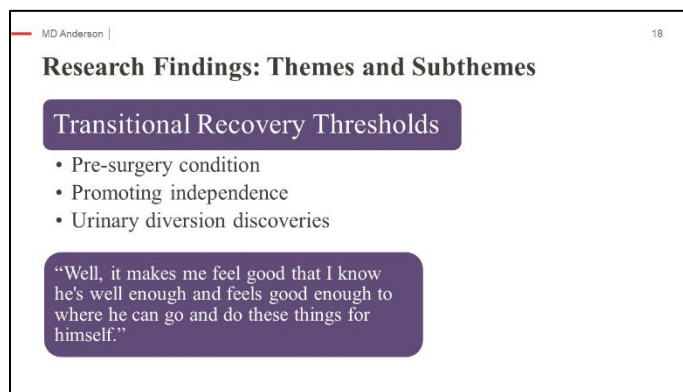
So COVID-19 and the way that things were shut down, it was a horrible experience. A lot of the caregivers stated that it just added to their anxiety. And then the quote that I selected was exactly what I told you, "We found out on a Wednesday, saw the doctor on Friday, and then a week following that Monday we had the surgery." So there are multiple factors that go into the caregiver experience before pre-surgery. And like I said, it just can depend on how expedited the process is or how long the process is. And then just you having to accept that cancer diagnosis. And then here you are at the surgery and then here's this mountain of information that you have to digest in a short period of time. And then after surgery, it's like you go home with this new baby and it's like, "Well, what do we do now?" But again, the caregivers expressed it's a partnership. They felt like it was teamwork and they did it together.

So one of the other major themes was seeking and accepting knowledge. So a lot of the caregivers detailed how they went on self-initiated education. Meaning they went to Dr. Google, they went to a BCAN website, they went to Facebook, and they reached out to any and everybody as a resource to gain knowledge prior to surgery. So they said that, "Yes, we did get the information from our outside resources, but we also got resources from our surgery team, or whether it be the wound ostomy nurse or it was the advanced practice provider. And then what I've learned is a lot of practices around the nation, they don't have an advanced practice provider, so they receive a lot of their information from nurses as well.

And then finally, the diversion education. So a lot of the caregivers expressed even one of the biggest decisions they all had to make collectively was deciding on a urinary diversion. Now of course, that decision is made, it's an individualized decision. Because they were like, "Yeah, my family member was very adamant about having a neobladder, but they have arthritis and just manipulating the different flushing and manipulating the different tools, it just wouldn't work out." So they ended up moving forward with an ileal conduit. So all of that education was factored into their decisions. And then ultimately it was, I coined it the home adventures. Where a lot of the things that they were taught, it was like, "Okay. Yes, you taught us the book, but the reality at home was quite different." I'll never forget one caregiver had mentioned, "No one ever told us the benefit of silk pajamas." And I was like, "Well, tell me more about the silk pajamas."

Brandon Sterling:

And they went on to explain, "Well, with all the different tubes and things that you go home with, it's the silk pajamas that make it easiest for everything to move around without getting caught in your clothing." And I was like, "Wow, that's actually a great thought. I never thought about that." And here's a quote from one of my caregivers, "We read lots of materials, of course, we talked to physicians, nurses, and they explained it. Of course, internet search, and we were just looking." And that's one thing I always get a little afraid of is that just looking part. Because with resources like BCAN, it's like patients shouldn't have to go down the rabbit hole of the internet. BCAN has a one-stop shop of all of the resources that you would need to be successful before and after surgery. So if there are any caregivers on the line, just check out their resources, they're top-notch, I promise.



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Research Findings: Themes and Subthemes

Transitional Recovery Thresholds

- Pre-surgery condition
- Promoting independence
- Urinary diversion discoveries

"Well, it makes me feel good that I know he's well enough and feels good enough to where he can go and do these things for himself."

And then the final theme that I discovered through my research was transitional recovery thresholds. So a lot of the caregivers attributed the success or the health status of their loved ones after surgery to how fit they were before surgery. Many caregivers explained, "I feel like they did so well, is because they worked out and they did everything they were supposed to do before surgery. They quit smoking, they started walking, they increased their activity

as we were told during pre-hab. And because of that, I feel like they did better." And then promoting independence. Now, this is very interesting because I have one caregiver who was like, they were very frank. They said, "Well, I enjoy being a caregiver, but what I really miss is going to dinner and I really miss going to lunch with my friends, so I'm really excited that my loved one is more independent because now I can get back to my regular life."

And many of the caregivers were very adamant about their loved ones learning how to do their stoma care because they were like, "Well, what if something happens to me or what happens if I can't be there immediately to help them manage an accident with the bag or something?" So many of them, they wanted to foster independence for their loved ones. So I wouldn't say it was tough love, but they were just instilling that trust in them that, yes, you can do this. You can do this. And as far as the urinary diverging discoveries, that's what I was touching on about the silk pajamas. And then a lot of the caregivers would basically say they really explained how to manage the tube and the bag drainage, but they didn't explain this certain bag. Because it's not uncommon that patients are discharged with a bag with a window because of they have existing stents.

So typically what they do is they keep that bag on until the stents are pulled and then you just transition over to the more permanent bag. So a lot of the caregivers have mentioned, "So with that, we learned how to use the other bag and not this bag." So again, a lot of them had expressed how they just made these small discoveries within the confines of their home, and that was little pearls that they will be willing to share with other caregivers. And I'm going to go ahead and promote that Inspire web forum

again, because those little pearls are invaluable. And those are things that the surgery teams may not be privy to, whereas again, we didn't go through the surgery, we never cared for a stoma at home. So those caregivers and patients who've gone through it, they can be a great resource to those who are just starting or those who are just embarking on that surgery journey.

Brandon Sterling:

And I pulled a quote from one of the caregivers, "Well, it makes me feel good that I know he's doing well enough and feels good enough to where he can go and do these things for himself." So essentially, many of the caregivers expressed in the postoperative phase, "The more independent that they are, the more that they feel they can do things on their own. I know that they're getting better, that means they have to depend on me less and less." But it's not necessarily a bad thing. Again, they really wanted to foster that independence and make sure in the event that anything were to change, that they could manage their diversions on their own.

The slide is titled "Research Findings: Caregiver Integration" and is presented in a purple and white color scheme. It features four bullet points, each preceded by a grey circle. The text on the slide is as follows:

- Caregiver involvement is key in the education process
- Diversion education central to patient and caregiver
- Recovery milestones were a positive indicator of recovery
- Time and experience reduced anxiety

And as far as the caregiver integration, just as a culmination of everything, caregivers again, are a cornerstone of enhanced recovery. They're a cornerstone of bladder cancer care, period. You can explain everything to the patient, but again, if you have all of these expectations of what needs to be done in the home or this fancy postoperative care plan, none of that will be instituted without the aid of a caregiver. So they must be included in the surgery

planning process, especially the diversion education. One of the main tenets the caregivers mentioned, "It's a team, it's a teamwork." So I would say to the providers out there, if you can't teach both, you're going to have to teach them again, make sure that caregiver is there. It's not uncommon during the pandemic, a lot of the caregivers would make recordings or videos of their own just to go back home and share with their caregivers.

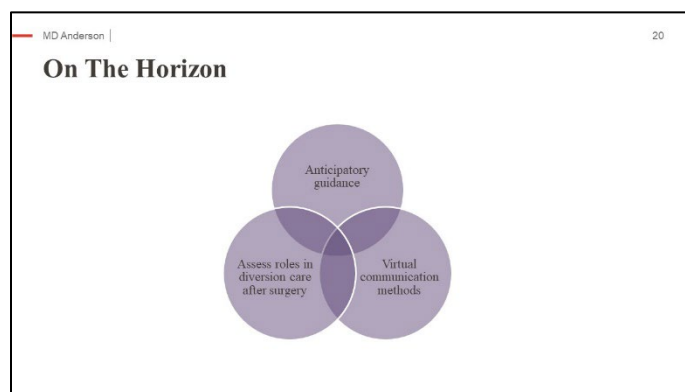
But luckily, we are beyond that. But still, the fact still stands that you must include those caregivers in any type of education, in any type of home program, anything. You can't do one without the other. You must have caregiver involvement. And then of course, the recovery milestones are a positive indicator of recovery. Man, when I had a couple caregivers, they were like, "Oh, man, just the fact that they ate a whole meal, I knew they were getting better." Or, "The fact that they could make it to the mailbox and back without getting out of breath, that just made my day because that was just an indicator that they're getting better." Or as I like to coin it, they're learning their new normal. So once things get settled, caregivers just express such a great amount of relief that things were becoming normal.

Brandon Sterling:

And then the time and experience reduced anxiety, meaning the more that they got better at changing the, or excuse me, during the diversion care, changing the ostomies, the better they got at it, the less

they had anxiety. Again, once they started to see their loved one getting back to normal or getting close to their new normal, it started to reduce anxiety. And one thing that I always would tell patients and even tell my caregivers in the hospital is like, "You are the first line of defense in the home for your loved one." Meaning that if a patient doesn't pass the eye test, that is a great time for you to reach out to the surgery team. And the eye test could simply be, "They don't look well today."

Now, as a caregiver, we don't expect you to immediately give a medical diagnosis, "Oh, I think they have a UTI." Or, "I think this is happening, or some type of infection." It could just be, "They're not looking good today." Or, "I don't feel like something is quite right." That is the optimal time to reach out to the surgical teams and express your concerns and then let us know so we can order the appropriate diagnosis or even bring you into the clinic for an assessment. So caregivers in that eye test saves lives. It saves lives.



And then on the horizon, and when I say on the horizon, these are just different aspects of care that I look forward to exploring with caregivers is the anticipatory guide. How do we really fine tune and hone in on those personalized care plans for patients in regard to enhanced recovery? Because you can't cookie cut any of this. A lot of this, you must look at each patient and caregiver individually and come up with a care plan to anticipate their needs. Like I mentioned,

what about those patients with poor mobility? What about those patients who may have arthritis and they can't manipulate the ostomy or the neobladder tools like they can, do we need to get an occupational therapist consult or a physical therapist consult to come up with some neat hints, tips and tricks? Do you have a ride home? Do you have resources in the home?

So these are things that we can definitely hone in on to make a more personalized experience. And as far as the virtual communication methods, I think BCAN is already advocating for telehealth on a national level. And of course it varies from state to state. And in the state of Texas, it was not addressed this legislative session, but hopefully in the next one, they will address the whole virtual care debacle. Because with us being a major cancer center basically on the Gulf Coast, Texas is a large state, so to have those patients lose that ability to connect to their providers virtually, it would be a huge loss. Because a trip across Houston, Texas where I am can be at least two hours. So just imagine having to travel from a different city around Texas to Houston. It could be quite cumbersome, especially if you're post-surgery or if you're having some type of surgery complication.

Brandon Sterling:

And then assessing the roles in diversion care after surgery. I really think we can hone in more on the needs of caregivers in regard to diversion care to either increase their confidence. Because a lot of it was, "I just don't feel confident. I just feel like this isn't... I don't think I'm doing it right." So how do we increase that confidence? How do we measure that confidence? And then I think a great item to explore

is what is your measure of success when it comes to diversion care in the home? And then with that definition, how do we apply that to other caregivers and patients across the board? So the opportunities are very rich out there for us to explore these different aspects of bladder cancer care, specifically focusing on surgery. And I've made it my personal mission to do the best that I can to conduct these research studies and disseminate that information widely.

But like I said, for those caregivers out there who are on the call, BCAN's resources are invaluable. And not only invaluable, they're free. So you just have to log onto their website and they will get you hooked

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up with those different resources, and then they can help you navigate the Inspire platform. That way you can have access to discuss all of these things with other caregivers throughout the nation and the world. So with all of that said, I wanted to thank you for listening to my presentation. Here are my references and then I'm going to stop sharing so I can answer your questions.

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