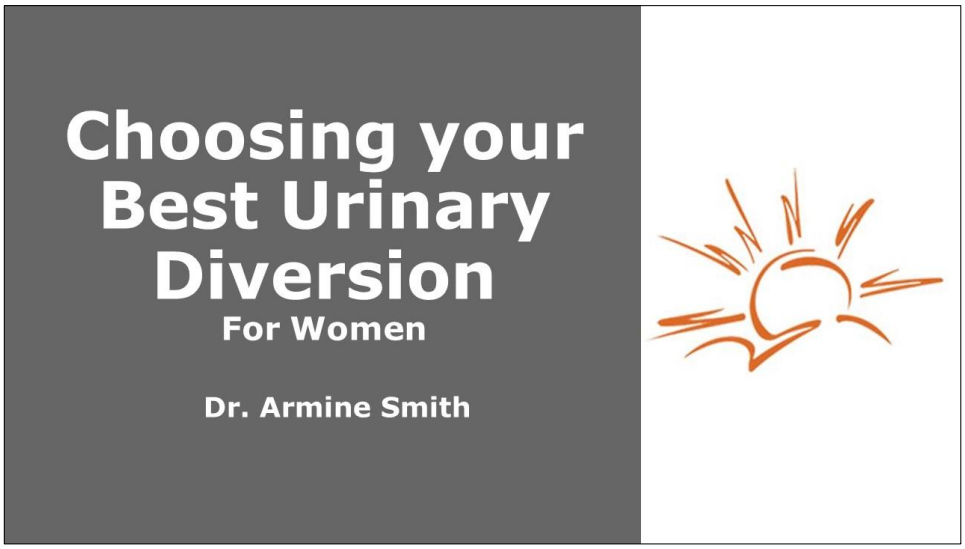


Stephanie Chisolm:

Hello and welcome to Selecting Your Best Urinary Diversion. My name is Stephanie Chisolm. This program is for women, and I am the Director of Education and Advocacy at BCAN.

we are really delighted today to really talk about the various types of urinary diversions that are available to you as patients when that radical cystectomy is your treatment option. That would include an ileal conduit, a neobladder, and an Indiana pouch. And we're really thrilled that Dr. Armine Smith from the Kimmel Cancer Center and Sibley Memorial Hospital, and she's also from Johns Hopkins Hospital, is here.

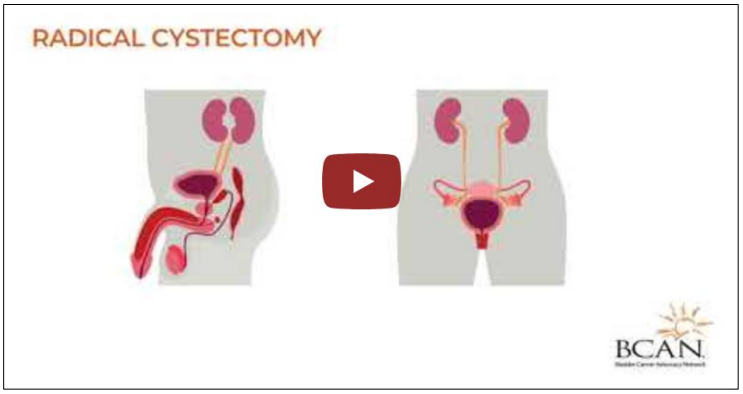
Dr. Smith's research interests and her clinical interests focus on women in bladder cancer. And as a urologist, Dr. Smith has performed many radical cystectomies and she's here to tell us how she and her patients together determine the best urinary diversions.

A spoiler alert, there's no best urinary diversion, although probably each of our speakers, our patient speakers might tell you that theirs is the best, it really is an individual decision. We're also really delighted to welcome three patient advocates from our Survivor to Survivor program who are going to discuss their radical cystectomy decisions and their life after their bladder removal. So Karen, it's nice to have you and Anita and Mary, thank you so much for giving us your time.

Stephanie Chisolm:

Before we begin, I would like to share a short animation. It'll kind of set the stage for everything that Dr. Smith is going to share with you.

Video Audio:



Cystectomy is a surgery that involves the removal of the bladder. The most common type of cystectomy is known as a radical cystectomy where the bladder and nearby tissues and/or organs are removed. After the bladder is removed, the surgeon also needs to create a new way for urine to be stored and leave the body. This is known as a urinary diversion.

A common type of urinary diversion is called an ileal conduit. This is when the surgeon creates a new tube from a piece of intestine that allows urine to pass through and out of the body via a small surgically created opening on the stomach known as a stoma. The urine then drains into a small pouch that fits over the stoma and attaches to the skin with an adhesive.

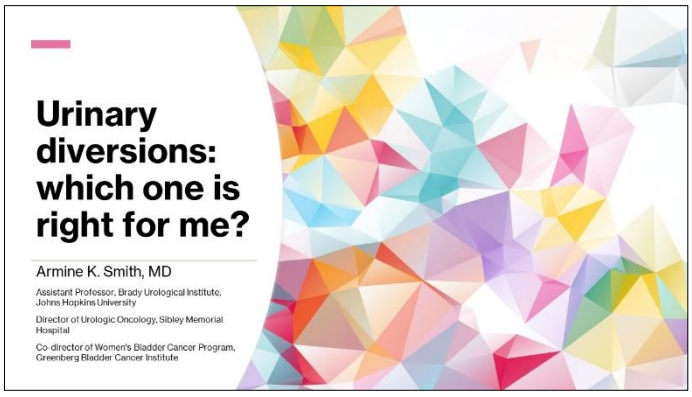
Another common type of urinary diversion is called a neobladder. This is when a new bladder is made, usually constructed out of a piece of intestine and attached to the urethra. In some cases, a continuous cutaneous pouch, CCP or Indiana pouch, is created using the small and large intestines to create an internal system of urinary storage. This pouch or reservoir is connected to the skin by a stoma, a small surgically created opening on the stomach, and is periodically drained via a thin tube or catheter. Learn more at BCAN.org.

To watch the video use this link: https://youtu.be/S2QKwhW8pds

Stephanie Chisolm:

Okay. So, Dr. Smith, I'm going to turn off my video and let you chat and share your screen.

Dr. Armine Smith:

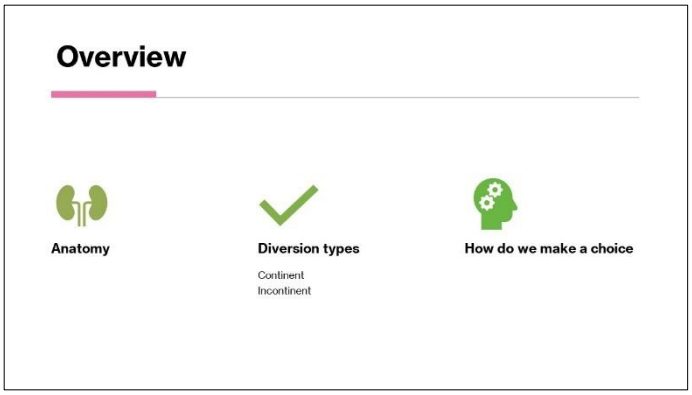


Thank you, everybody. Thank you, friends, for joining me today to discuss this topic. So we're going to talk about the urinary diversions as Stephanie kind of set the stage for us earlier and talk a little bit about the decision-making and why we decide to proceed with one diversion versus the other.

So my name is Armine Smith. I work at Radiological Institute of Johns Hopkins University. I'm a director of Urologic Oncology Sibley Memorial Hospital here in DC, and I also co-direct the Women's Bladder Cancer Program as part of the Greenberg Bladder Cancer Institute.

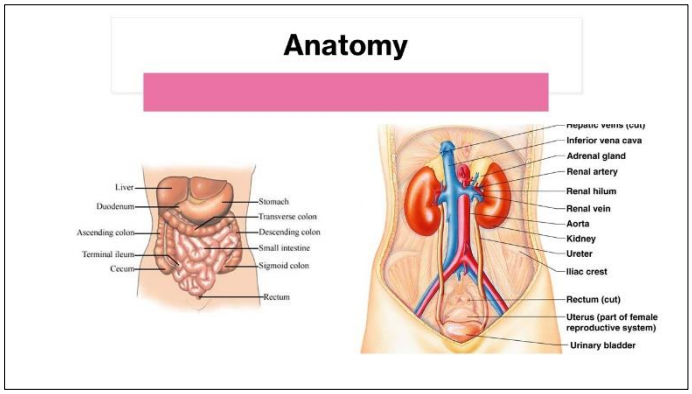
Dr. Armine Smith:

So to talk a little bit about the anatomy, which we've touched on a little bit briefly, we'll talk a little bit about diversion types just because it's not intuitive to understand what happens when these types of diversions are made. Then we'll move on to talk about how we make a choice about these.



Dr. Armine Smith:

So the anatomy of the abdomen and the peritoneum and retroperitoneum, and the reason I'm bringing it up is because we use a lot of these bowels and I think we use some portion of the bowel for a certain diversion and a different portion for a different diversion. So I think it's important to see it.



If we look at the initial layer of the abdomen as we enter, there are bowels and the bowels are not in the frozen state. They kind of move around and they fill around. I say that, because patients ask me, they're like, "If you take something out, what happens? Is it like a void?" No, things move around and kind of rearrange themselves in the abdomen, and usually it's the bowel.

So you have the digestive tract that spans from the stomach through the duodenum and then through the small intestines, and they continue until they insert into the colon. The colon has also distinct anatomical area. So the right colon is also called the descending colon. There is the middle part or transverse colon, and then there is the descending or the left colon that then joins the rectum.

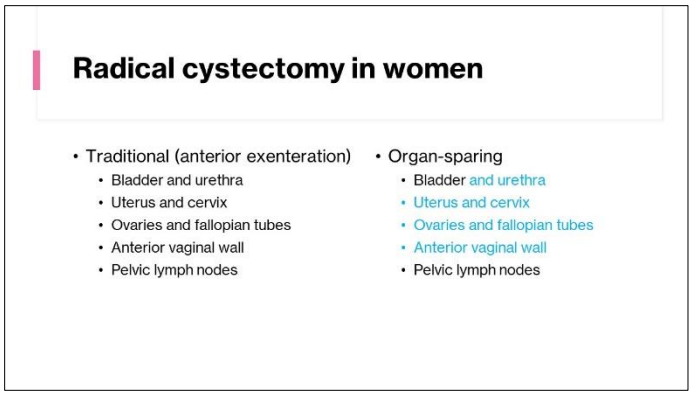
So if you peel off that first layer, we end up with the retroperitoneum, which is also an important part for us as a urologist, because it contains the kidneys. It contains the ureters that carry the urine from the kidneys all the way down to the bladder, which sits in the pelvis. These are just some large vessels that span the whole retroperitoneum that carry blood in our body. Behind the bladder in women sits the uterus and the cervix and vagina. Then at the very back of the retroperitoneum is the rectum, which is shown schematically here.

Dr. Armine Smith:

There are few ways to do a cystectomy. The traditional way is also called anterior exteneration, because what we do is remove kind all the organs in the anterior or the front part of the pelvis. So traditionally we removed bladder and the urethra, the uterus and cervix, ovaries and fallopian tubes. We would remove

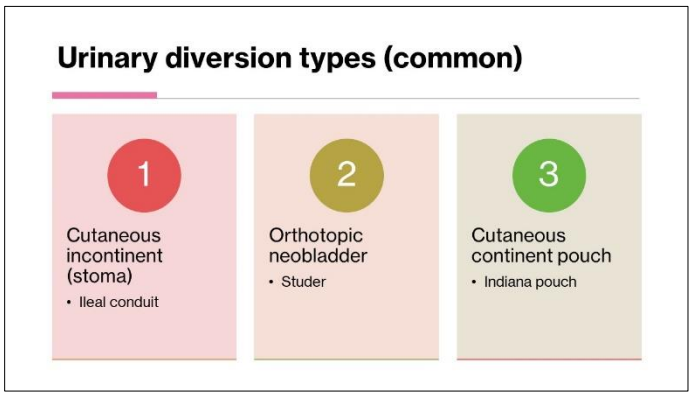
the anterior vaginal wall, pelvic lymph nodes, and that was the removal of the bladder pretty much for bladder cancer in women.

Nowadays, this kind of ancient view has started to dissipate a little bit. So we have better ways of managing women, and we have come with something called organ sparing cystectomy. For that, usually we remove the bladder and pelvic lymph nodes and the rest of the organs can be left in place in the proper scenario.



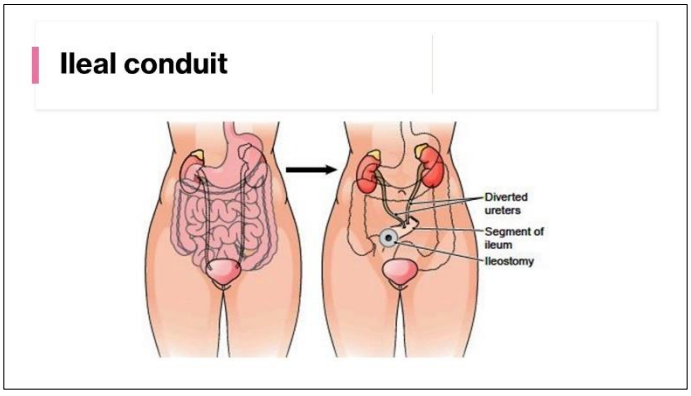
Dr. Armine Smith:

So moving on to urinary diversion types. Then the video had a nice little overview, so I'll try to match it with my more ancient slides. So we have the incontinent diversion or the stoma, or it's called ileal conduit. There is also the continent diversions, number two and three. So the orthotopic neobladder or most commonly performed diversion type, it's called Studer, orthotopic neobladder. Then there is the cutaneous continent pouch. The most common type that I've seen perform that's called Indiana Pouch.

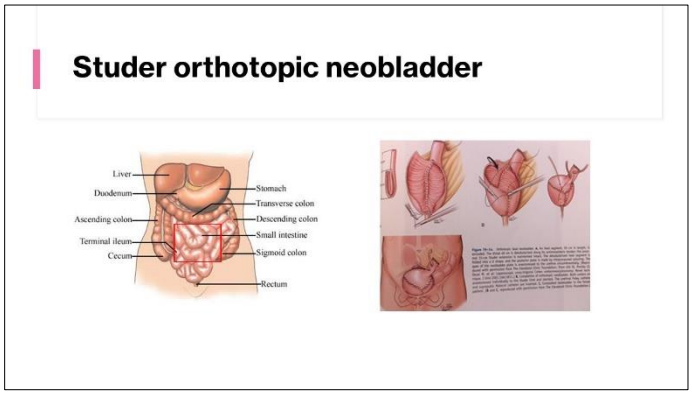


Dr. Amine Smith:

For the ileal conduit you see we remove the bladder, we remove kind of the bottom part of the ureters, and then we take a small portion of the small bowel at about 12 centimeters in size to 15 centimeters, and the ureter is plugging into the back portion of that conduit of that small segment. The front portion gets joined to the abdominal wall, and that is part that's called conduit or ileostomy. The pouch then goes on the top of it, it collects the urine and the urine drips kind of in real time as it's produced.

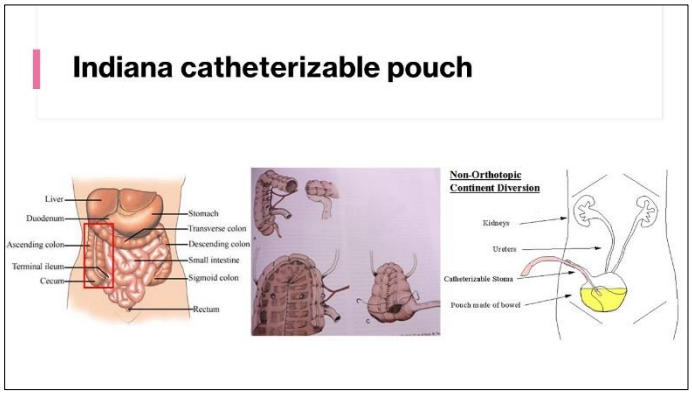


Dr. Amine Smith:



The orthotopic neobladder or the Studer orthotopic neobladder is constructed using about 55 to 65 centimeters of the small bowel, that is this bowel in the middle of the abdominal wall. We take this tube, we make the incision in the wall of the tube and convert the tubular structure into a spherical structure. So the back wall kind of gets joined together and the front wall gets folded on itself and we end up with this sphere that doesn't quite look so pretty, but that's the schematic of it. We have a little part that's called “chimney” that's sticking out from the top. And the ureters get plugged into this chimney and the most dependent portion of it gets joined with the urethra and that's where the urine would come out as the person urinates.

Dr. Amine Smith:

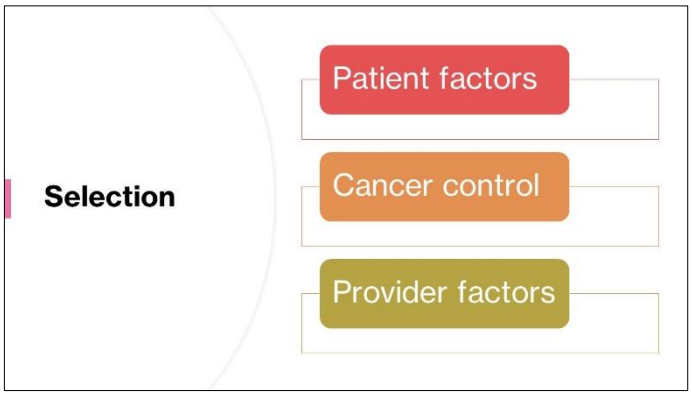


For the Indiana catheterizable pouch, what is used is usual the right colon or the ascending colon. So you take the whole length of the ascending colon, a portion of the transfers colon, and a little bit of a portion of the small bowel that's attached to it, it's called terminal ileum. Again, you detubularize it. So you make an incision in this tubular structure, put it together as a pouch in the back and then fold it over in the front, and it ends up being a kind of spherical looking shape, structure. The ureters get plugged in into the back wall of the pouch, and then we have this little part of the ileum or terminal ileum that becomes the stoma.

So if you look at this kind of cartoon presentation on the right, you see these kidneys are plugged in the back of the pouch. The pouch kind of fills up with urine. This is the stoma that is a very kind of a small diameter tube that gets plugged into the abdominal wall or the belly button area. One would pass a catheter through to drain the urine in place. So for this catheterizable pouch, we use the body's natural continence mechanism or the terminal ileum. And that actually is a mechanism that prevents the urine from spilling over as it fills up the pouch. That is our mechanism.

Dr. Amine Smith:

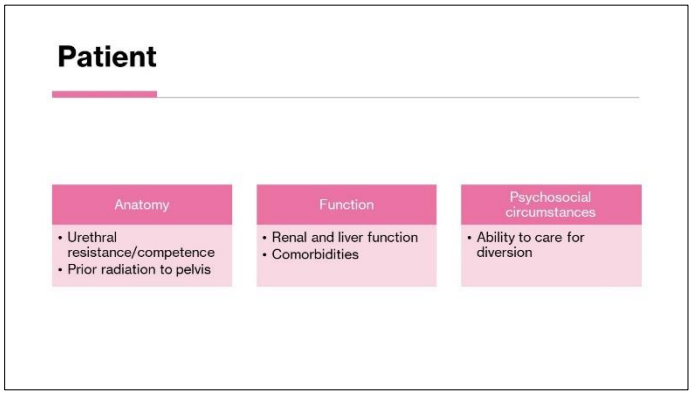
So the way we come up with the answer of who gets what, is based on multiple different factors. So we have patient factors, we have the cancer itself, and then the provider factors.



Dr. Amine Smith:

So patient factors are multiple. We have to consider the anatomy, the function of the patient, and then also the psychosocial circumstances. So let's say for anatomy, we want to make sure the urethra, which is going to be the outlet for the neobladder, does not have scarring. So it doesn't have excessive resistance and it has competence to pull the urine in place, because we don't want you to have a neobladder and leak like a seed from it.

For other factor of anatomy, people who have radiation to the pelvis in the past for other reasons like cervical cancer or colon cancer and some things like that, and the structure in the pelvis form more scarring and they have less blood supply, so they're more prone to inadequate healing and things like that. So this ends up being a not absolute contraindication, but soft contraindication to certain kinds of diversions that we may offer.



As far as the function, the kidney function is very important, liver function as well. So there are some cutoffs at which we know the kidneys and the liver cannot handle the solutes. And the reason it makes a difference is because the bladder wall is very different than a bowel wall. So the permeability of the salt and the solutes in the urine through the bladder wall is very different than what would happen if you use a bowel as the bladder. So when you have a pouch that holds the urine in place and a lot of the solutes come out, the kidney should be able to filter them out and get it out of your body. And if the kidney function is already impaired in some people for a variety of reasons, including neoadjuvant chemotherapy or other, like diabetes and blood pressure, we know the kidneys can't cope with all this overload of solutes and then people start running into trouble.

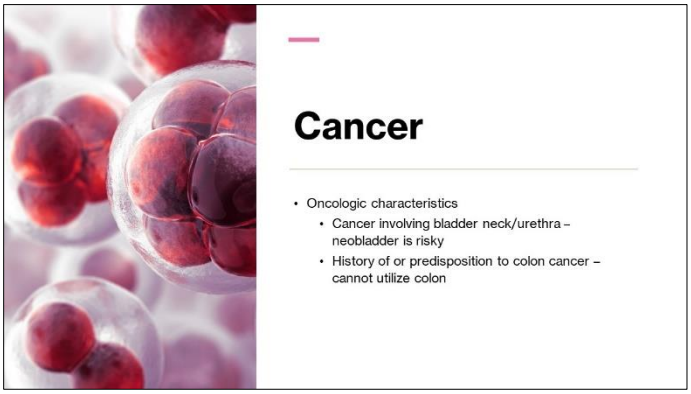
Some things that we'll look at is the comorbidities, meaning what kind of medical issues does the patient have? So if the patient has a lot of cardiac issues and we're trying to get them quickly into the surgery and out of the surgery, adding additional two hours or hour and a half to construct a very complex bladder does not make a lot of sense, because then we're not helping this patient, we're putting more risk into the surgery. Other things and other scenarios can arise, but this kind of the one that comes to mind the most frequently when we make this decision.

Dr. Amine Smith:

Then the psychosocial circumstances usually, I mean the ability to care for the diversion and to talk about some examples. So some of these diversions have catheters that need to be inserted, the catheters and the pouch that needs to be flushed. Some diversions require more stoma maintenance than others. You have to set voiding intervals, because the bladder is done and the nerves that supply the bladder are disrupted. So the body does not have the ability to have this automatic feedback that tells you, "My bladder's full, I need to go empty it." We certainly don't want to overstretch the new bladders and cause them to not function properly. So most of the people have to set alarm at three hours or three and a half hours, four hours and wake up once or twice at night to empty this, at least continent diversions.

There's maybe need for intermittent catheterization, and for some people it's really kind of a no-no. So the word catheter sends them far away from the picking of that urinary diversion. Then the access to supplies and medical care. There are some people who travel for work, they may travel for leisure, they want to not be bound by needing to carry large amounts of catheters or pouches to exchange the adhesives and things like that. So all these kind of things also come into play when we have this conversation.

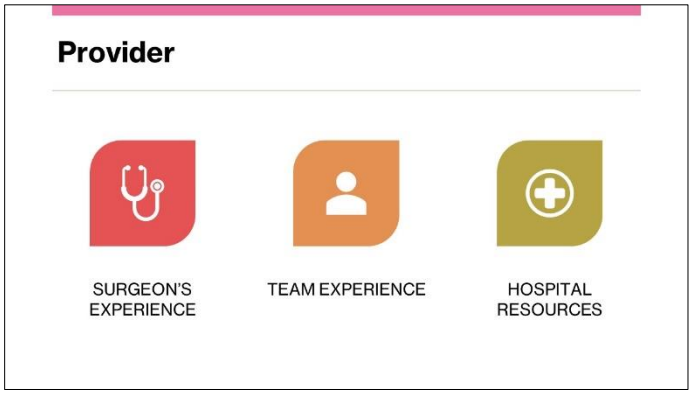
Dr. Armine Smith:



Now, the cancer factors, so our first goal is to rid you of cancer. So if we're going to do something that's going to compromise that, that's not in the best interest of the patient. So there's some things that we'll look at when we decide if it's safe to leave the urethra in place and put together a neobladder with it.

So if you have a cancer that's at the bladder outlet that joins the urethra or the urethra itself, leaving that portion of the urinary tract in place, risks leaving cancer in place. So for these patients, usually neobladder is too risky. We would not offer that. If you have a history or a predisposition to colon cancer, we unfortunately cannot utilize the colon. So Indiana pouch is out of the question for that. So those are just some things to keep in mind.

Dr. Armine Smith:

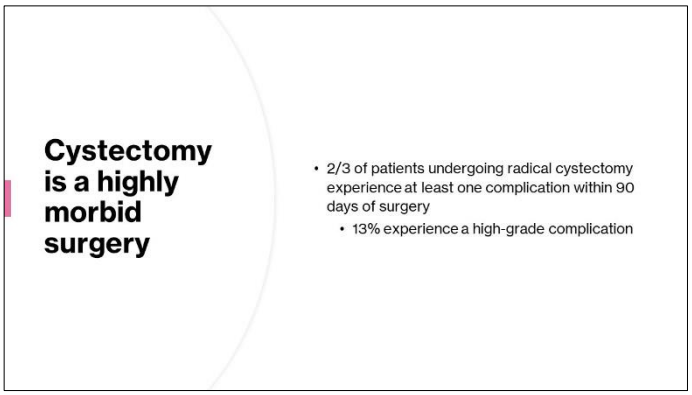


The provider factors and the system factors are usually also multiple. There's the surgeon's experience. Not every person who does radical cystectomies is familiar and has the training and experience to offer all three. You definitely don't want to push your surgeon to do something that he or she is not comfortable with. With these kinds of diversions you have to have an experienced team, you have to have nursing that's able to help you along. You have to have a stoma nursing, you have to have somebody who's going to answer the phone when you have some issue with this continent diversion or the pouch or the conduit.

Then there are hospital resources. This is a difficult surgery, complicated surgery. Patients are usually not the healthiest, because they're older and have other medical issues, sometimes smokers and sometimes not. So the hospital itself matters where you can get tertiary care is needed, where you can get ICU care is needed to have this radical cystectomy. The reason I'm belaboring this point, is because cystectomy is a highly morbid surgery, meaning it's fraught with potential complications that can happen during surgery and after surgery. So from analyzing all of our experience from different institutions in literature, we know that about two thirds of the patients who undergo radical cystectomy will have at least one complication in a postoperative period, and that's usually about three months.

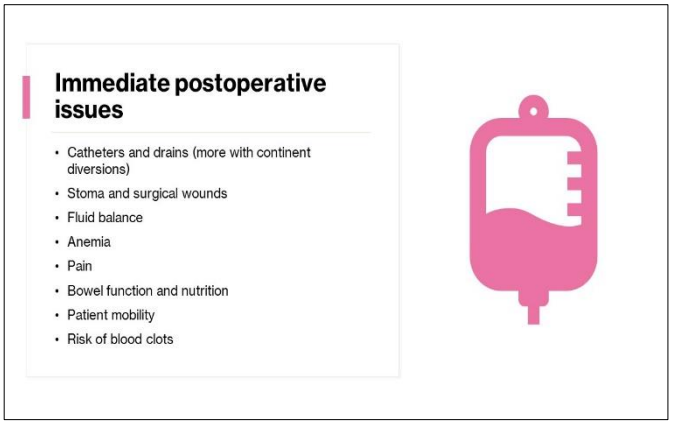
Most of the complications are fortunately mild, but about 13% experience a high grade complication.

Dr. Armine Smith:



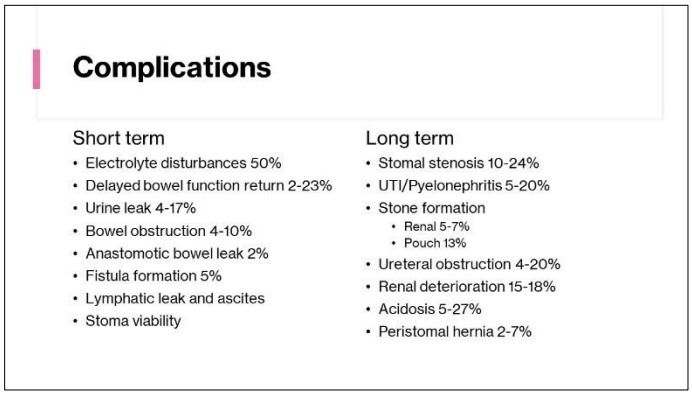
The reason, again, to talk about this a little bit more as we're selecting the urinary diversion, is because there's a lot of stuff that's going on. You have to have a surgery that's a fairly difficult surgery already. There are immediate postoperative issues that patients can be dealing with. Do we want to make things more complicated or less complicated for the patient? These are the things that come to mind.

Dr. Armine Smith:



So usually when patients leave the operating room, they come out with multiple catheters and drains. There are more catheters and drains a lot of the times with the continent diversions, just because the anatomy is more complicated. Patients deal with the stomas and surgical wounds. It's tricky to maintain a good fluid balance. People deal with the anemia, which is inadequate amount of red cells, whether it's due to cancer, to chemo, to blood loss during surgery. People deal with pain while recovering from surgery. The bowel function and motility are an issue as you probably hear one of, or at least one of our patient advocates who will share their experience. Patients are more immobile after surgery, their risks of blood clots. So the patients are already dealing with a lot of things.

Dr. Armine Smith:



Some of the complications that go hand in hand with the radical cystectomy and some are more inherent to certain urinary diversions and some are just all across, because of the removal of the bladder. So people deal with the short-term complications, which are electrolyte disturbances, it's about 50% of people will deal with it right away, right after surgery. Some people will have delayed bowel function return. Some people may deal with the urine leak. Some people may deal with bowel obstruction, bowel leak, official formation. Fortunately, a lot of these are small. The percentage of people who will have issues with this are small, but a lot of things are getting detached from each other and reattached to each other, and that can cause problems.

Now, long term I think becomes a little bit more important when you select a certain kind of urinary diversion, because we know, so let's say for Indiana pouch, the rates of stomal stenosis can be up to 10-24%. That's because it's a small channel that gets used multiple times a day and can devolve scarring. If you're willing to take that chance and that's great, but it's just something to keep in back of mind.

Stephanie Chisolm:

Dr. Smith, can you just explain what stomal stenosis is for those who don't know?

Dr. Armine Smith:

Sure. So like I said, it's most pertinent to people who have the catheterizable pouch and they have that very small stoma that's flush and comes out to the skin, whether the belly button or the kind of right side of the abdominal wall. That's where the catheter is passed through multiple times a day to drain the urine. The scarring can build up at the outlet of the stomal joint, juncture, to the skin or a little bit even down closer to the pouch. What that would do is, that would just make the catheterization difficult. Fortunately

the revision of the stoma is a fairly straightforward surgery. So you can do some nip and tuck and make the skin a little bit bigger to pass the catheter, but it's something that's known to happen in people who have these stomas and it's really just a overuse injury to the stoma.

Stephanie Chisolm:

Thank you.

Dr. Armine Smith:

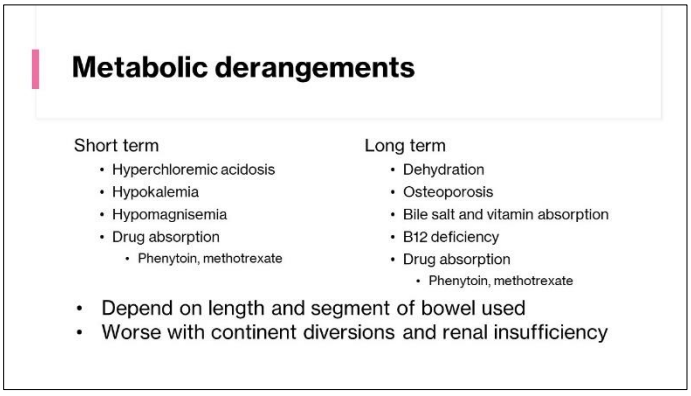
The UTI and pyelonephritis, I mean, these are fairly common things. For some people, they just can't get rid of these UTIs. And we know that people with the Indiana pouches and orthotopic neobladders, initially, in the first three months, have more rates of infections than the conduits. However, the conduits over kind of the lifetime of the individual, will have higher chance of infection and it's very much individual dependent. Some people just have the ability to colonize the urine and get sick from it over and over, and some people just never see a single UTI in their lifetime. So that's just something that kind of also I get asked a lot when people come to me and it's something that just needs to be dealt with promptly, because when you don't have a bladder and you have the infection, it very quickly turns from a very simple infection to a full-blown kidney infection, land you in the hospital with sepsis and a very complex hospitalization.

Stone formation. So because there are issues with the fluid balance and people sometimes struggle to maintain good hydration with these urinary diversions in place, there is an incidence of renal stones and about 5-7%, not overwhelming amount. Also, people who have Indiana pouch sometimes will form mucus in the urine and the mucus is also very individual dependent, some people form less, some people form more. There's some dietary intake that can prompt you to make more mucus such as dairy products. And if this mucus is not flushed out properly, it can turn into pouch stones, then those need to be handled over time if that happens.

So urinary obstruction or urinal obstruction, renal deterioration and acidosis are not quite as dependent on the type of the urinary diversion, but they can happen in all three of these diversions. Acidosis or the metabolic derangement can happen more in the continent diversions. And again, it depends on the type of the bowel, and I'll talk about it a little bit more on the following slide. For people who pick a ileal conduit, there's about 2-7% incidents of parastomal hernia that can kind of cause obstruction or disfigurement and can be dealt with in multiple ways as well. So the conduit is not completely straightforward diversion that can carry you through your life either.

Dr. Armine Smith:

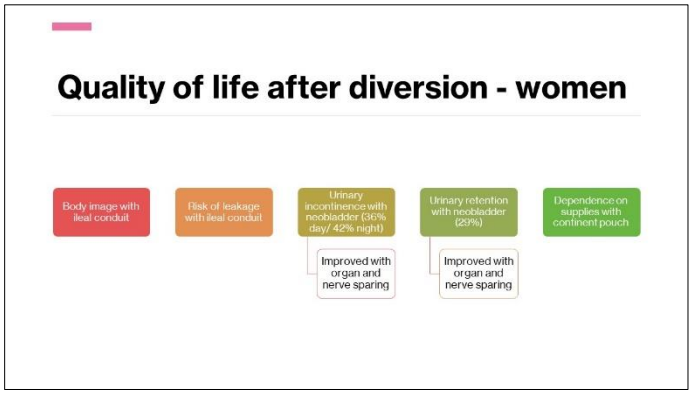
Now the metabolic derangements or the electrolyte derangements can happen short term and long term. So short term there can be increased acid in blood. So hyperchloremic acidosis it's called. We can have low potassium and low magnesium. Also, certain kinds of diversions can affect the drug absorption. So some that come to mind is methotrexate, they're absorbed differently and you'd have to modify the medication intake when you have a different



kind of diversion. Then long-term metabolic derangements, there are sometimes kind of preselected based on these short term disturbances that happen, people can get dehydrated.

The acidosis that is happening long-term can cause osteoporosis. Using the longer segments of the bowel can predispose you to malabsorption of bowel salts and vitamins, special B12 deficiency. Nowadays, we have a little bit of a different technique, so we'll leave a little bit longer channel at the terminal ileum if possible and that circumvents some of these malabsorption issues, but they're still there. If you have Indiana pouch, you have to have B12 checked every year for the rest of your life. Again, the drug absorption can be an issue in long term as well. So these metabolic derangements depend on the length and segment of the bowel that is used. Then it can be worse with continent diversions and it can be certainly worse with renal insufficiency and liver insufficiency as well.

Dr. Armine Smith:

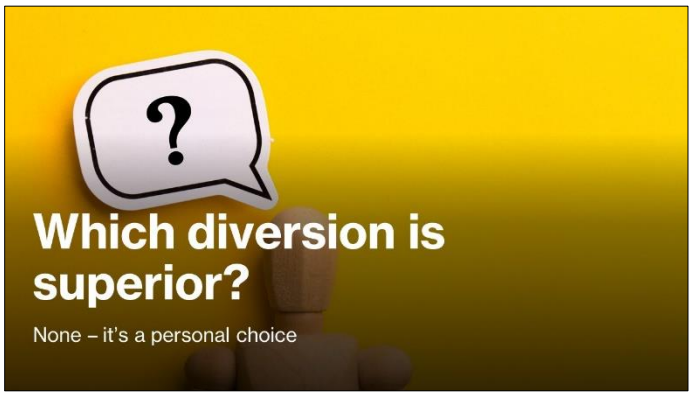


So looking at the quality of life after diversion, especially in women, not certainly only happening in women, but these are a lot of things that I've heard from my women patients. There are some people who have issues with the body image, with the ileal conduits, and people just don't like the idea of having the urine present. They think there's a smell that's associated with that and they worry about the risk of leakage from the ileal conduit, which can happen if the stoma appliance comes loose throughout the day. That is just kind of the issue with that. These patients are usually the ones that kind of stay away from the ileal conduit and want to have something more that's hidden inside of the body, so a continent diversion of some sort.

For the neobladder, the usual kind of things that we see are urinary incontinence or urinary retention. So in women, these numbers are reported as about 36% of patients experience incontinence during daytime. And about 42% of patients will experience incontinence at night. Then the urinary retention with the neobladder up to a third of the patients can, throughout their lifetime, go from having a perfectly functioning neobladder to a neobladder that doesn't drain on its own. Sometimes we don't know the answer of why that happens, whether it's the kinking of the pouch, whether it's the nerves that are supplying the area that needs to be drained, it still remains to be seen.

The good news is, these numbers are improved with these newer organ and nerve sparing techniques, but there's still something that I always bring up to the patients when they think about the neobladder, because you don't want to leave them with the surprises after surgery. For Indiana pouch, again, the things that can be bothersome to some patients are the complete dependence on supplies. So you can't travel anywhere without a catheter and most of the people need some sort of a irrigation solution to irrigate their pouch to get rid the mucus and things of that nature.

Dr. Armine Smith:



Which diversion is superior for a patient? We've had a lot of studies look at this, a lot of questionnaires sent out to the patients and the answer is, none of them are superior. It's a personal choice. What we know is that once the patient is counseled appropriately, told about all the potential risks and all the potential issues that can go hand in hand with the diversion that they choose, if they choose it, they're usually happy with it. I have not really had anybody who came to me and said, "I really want to change what I have to something else," which sometimes we can do that. So if there's a person that's say very unhappy with a neobladder or develops some sort of issue with a neobladder over their lifetime, it can be converted into a ileal conduit. And Indiana pouch can also be converted to a conduit. Usually you can't convert catheterizable pouch to neobladder, just because the anatomy doesn't work. Then you already have a large amount of bowel that's missing from one diversion and you just can't keep chopping away at the GI tract and have a functioning GI tract.

Dr. Armine Smith:

So the takeaway point is, if you do your research, have a very frank conversation. The other thing I do with my patients, I always tell them to talk to other patients who have a certain kind of a diversion that they're interested in, just to understand what it's like to live with these diversions. I tell them usually, "You don't even have to tell me now what you want. Just wait and do all your research, talk to people, check out the BCAN website. And about a week before or a few days before the surgery, we can decide what to do for you, because this is ultimately the change that's going to happen to your body and that's what's going to stay with you for the rest of your life. So you just want to make sure you make the right choices with the right knowledge." So that is all for my presentation, Stephanie.

Stephanie Chisolm:

That was fabulous and incredibly thorough. And I think one of the major points that I always like to stress to people is, when you don't know, you go to the pro. But going to the expert that has done multiples of the type of diversion that you are selecting is really the best thing, because they know how to handle a lot of those nuances, if there were any problems that they can make adjustments. There aren't many, but there are some urologists that are well-versed in all of the different techniques. I think it's definitely to everybody's advantage to go and ask people that specifically have done multiple types of diversions. I love

the fact that you really did a nice job of talking about what happens when you take away some of the bowel and use it for something else. What are some of the impacts that you might have.