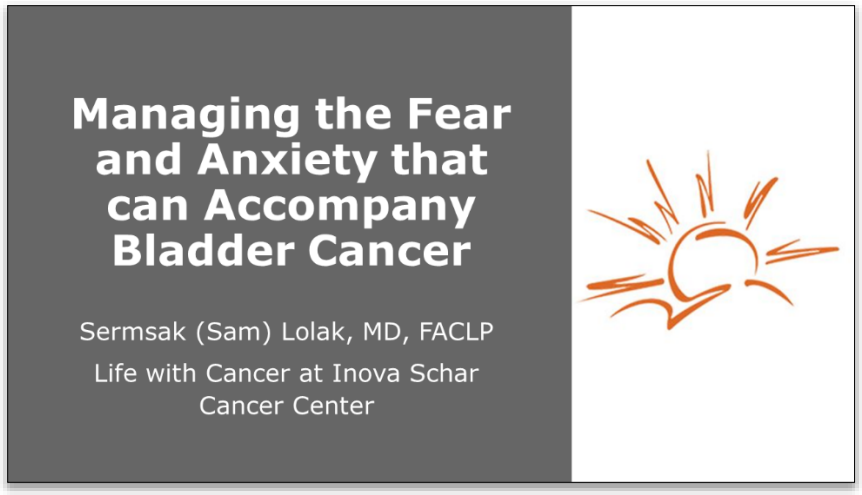


Stephanie Chisolm:

Welcome to Managing the Fear and Anxiety that can Accompany a Bladder Cancer diagnosis. Any cancer diagnosis can cause fear and anxiety, but bladder cancer with its high rate of recurrence can be very fearful and it can also lead to a great deal of distress, both financial distress and personal distress. Today we're going to talk about how to manage the fear and anxiety that can accompany bladder cancer. This session is really meant to highlight and provide strategies to address the many stresses that accompany this diagnosis.

If you have questions beyond this call or if you think of something later on, I'm delighted to let you know about BCAN's new partnership with CancerCare on our bladder cancer call center, which is open during regular business hours, Monday through Friday, Eastern Standard Time. And all you need to do to speak to a licensed clinical social worker is call 833-ASK-4-BCA. Tonight, BCAN is honored to host this important conversation to help you navigate and understand these difficult feelings and issues. I'd like to welcome Dr. Sermsak "Sam" Lolak from Inova Schar's Life with Cancer Program. Dr. Lolak specializes in the management of mental health issues like depression and stress and anxiety in the context of cancer diagnosis and treatment. And this includes drug interactions between cancer therapies and psychiatric medications. He also has a special interest in mind, body and contemplative practices, especially mindfulness and compassion cultivation. And I know he includes that in his slides. And he's very aware of the clinician burnout issue as well. I'd like to welcome Dr. Lolak to our presentation and I am going to turn my screen over to you.

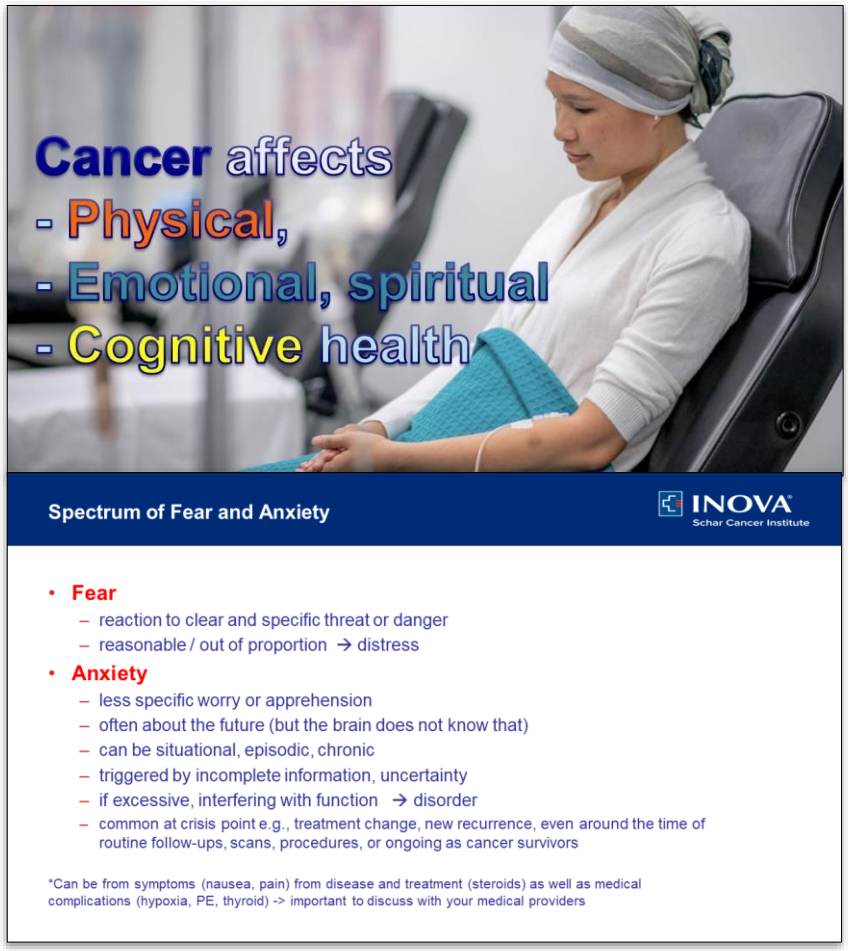
Dr. Sam Lolak:

Thank you. Thank you so much Stephanie, and thank you BCAN for having me today. And also I want to thank Morgan who is in the background helping with everything today. First I'm going to share my screen. Just a slide show. I don't hear you, so I'm assuming that everyone see my screen.

Stephanie Chisolm:

Yes, we can see it.

Dr. Sam Lolak:

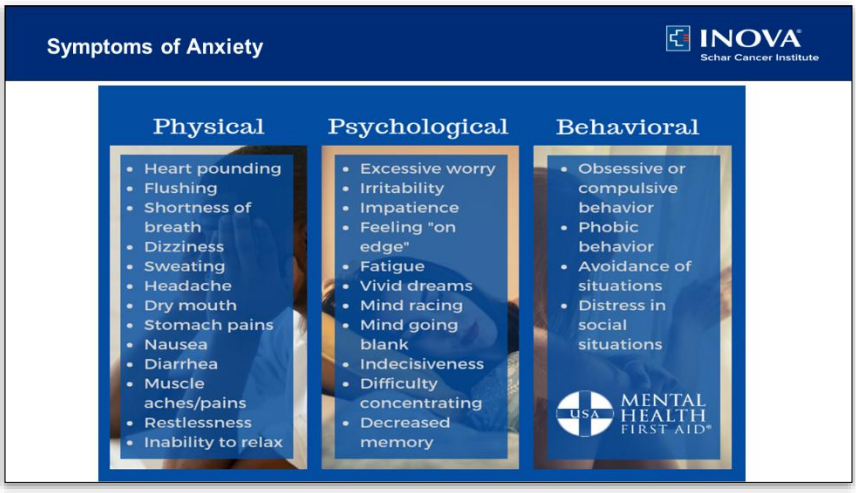


Thank you. Today we are going to be talking about some of the strategies that can help you manage anxiety and fear that accompanies the bladder cancer diagnosis and treatment. So as you know, cancer not only affects your physical health, but also emotional, spiritual and cognitive health. And when we talk about fear and anxiety, the way I look at it is as a spectrum, right? Spectrum, meaning that there's one end that could be viewed as normal, normal fear, normal anxiety, and then on the other end of the spectrum it could be what we call dysfunctional or starting to impact your daily lives. So first, fear. Fear is a reaction to clear and specific threat or danger. It could be reasonable like when you have a difficult exam coming up and you have some fear or it could be totally out of proportion, which can lead to some distress.

What about anxiety? Anxiety usually is defined as a less specific worry or apprehension. A lot of time it's in the background, but it can come into the forefront when it's triggered. And it is often about the future. Most of the things that we feel anxious about, most of the time it's something that hasn't happened yet. But the trick is the brain doesn't know that. The reason we have anxiety or we feel anxious is because the brain wired mechanism to respond to the threat. And sometimes the brain thinks that something is a threat, even though it's actually not. At least it hasn't happened yet. The anxiety can be situational. I think of all of you here can relate to anxiety when you are waiting to see the doctor for the test result or the scan result, it could be episodic comes and goes, or it could be chronic running in the background for a long, long time.

And in the context of cancer, especially cancer diagnosis or even phases of treatment, anxiety can be triggered usually by incomplete information or the sense of uncertainty. When the doctor doesn't know the answers or the test results haven't come back or the treatment effectiveness is still not parent, right? There's a sense of uncertainty that can lead to anxiety. If the anxiety is excessive or it interferes with function, then we can classify it as an anxiety disorder. Anxiety is especially common at crisis point, for example, like I mentioned, whenever the treatment change, new recurrence or even around the time of routine follow-ups or procedure, could be on ongoing. Some people continue to have anxiety years after cancer diagnosis or even years after their cancer has been stabilized.

Dr. Sam Lolak:



I just wanted to point out real quickly that even though we talk about anxiety from a psychological perspective, it is also important to be aware that sometimes the symptoms of anxiety or the sense of feeling anxious could be from medical symptoms. For example, pain can cause anxiety or could be from the disease itself, like pulmonary embolism can cause symptoms of anxiety or the medication, for example, steroid or some chemotherapy. It is important to discuss with your medical providers, especially whenever the anxiety happens acutely without obvious stress. There are several symptoms of anxiety. If you look at these slides, a lot of these will be familiar to you. When we feel anxious, we feel like our heart is pounding. You feel sometimes short of breath, butterfly in stomach, even nausea or muscle tension.

And there's psychological symptoms, excessive worrying, irritability, mind racing, difficulty going to sleep. And then behavioral symptoms. Sometime being ruminating, obsessing over something or avoid of some situation. What about treatment of anxiety? There's several treatments that works for anxiety and most of the time some of the most effective treatment that we have for anxiety is going to involve some sort of counseling or psychotherapy. One type of psychotherapy that has really good evidence for anxiety is called cognitive behavioral therapy or CBT, which aims at trying to identify the pattern of thinking or thought that leads to anxiety. For example, catastrophic thinking. When you start to think of the worst possible outcome, usually a lot of people can relate to that, because that's what we do when we deal with some life altering events like cancer.

So this type of counseling or therapy can really help identify those thoughts and give you strategies to manage those thoughts and behavior so that it doesn't lead to anxiety. Other types of counseling or psychotherapy work as well. And there are techniques what we call in general relaxation exercise. This includes breathing techniques, in and out, deep breath, progressive muscle relaxation. And you can find out more information about this online, just go Google it. Tensing your muscle and then relaxing systematically from head to toe can help with that sense of anxiety. Or a technique that's called guided imagery. Stress management typically, generally will work. Healthy coping mechanisms, for

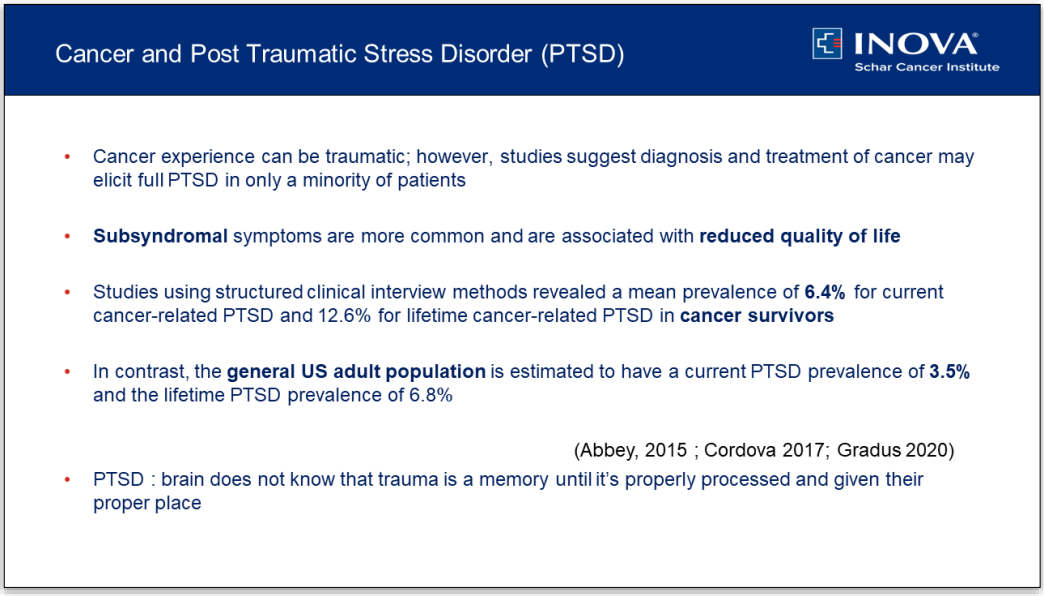
example, things like hobbies, spiritual practices, mind body intervention, mindfulness practice, yoga, acupuncture, massage.

Dr. Sam Lolak:

Those things work for anxiety, because not only we kind of manage the anxiety from the top down, starting with our thinking to anxiety behavior, but we can also manage our anxiety from the bottom up. Anxious thoughts make us feel tense, but if we feel relaxed, whether it's from breathing practice or doing yoga or massage, it can also send the feedback signal back to the brain that everything is okay now, what you worry about is actually hasn't happened yet, which can help also with anxiety. And then lastly, exercise actually has a lot of really good evidence that can help with anxiety. It's one of the most effective coping mechanisms that we have for anxiety, but you have to do it. It requires some effort and some discipline to do exercise. And then other self-care practices, diet, sleep as well.

And then lastly, medication, which can be helpful in many patients, especially when they're already doing those things that I mentioned but they still struggle with intense anxiety and there are several types of medication that we use for anxiety. This talk we're not focusing on that, but you can find those information pretty readily online.

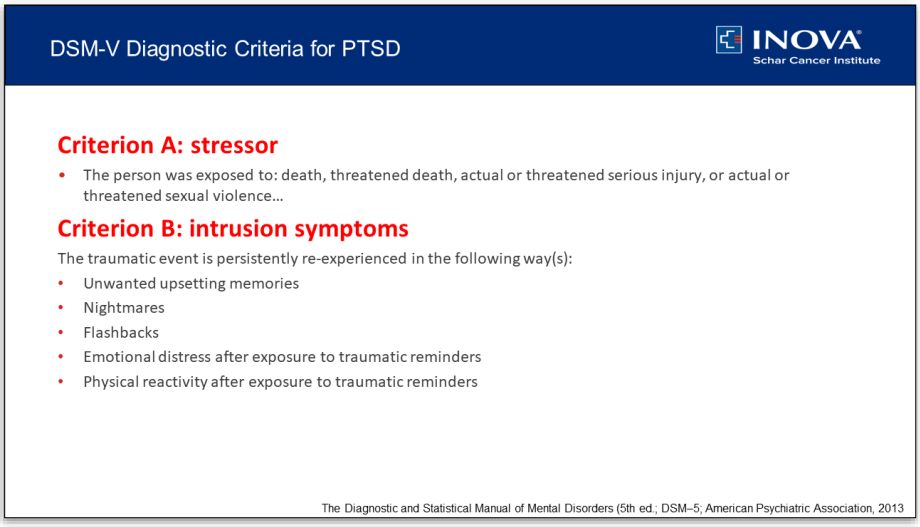
Then I want to spend the next part of my talk focusing on the concept of cancer and post-traumatic stress disorder, about PTSD. You might be familiar with PTSD from traumatic events like being in a war or sexual assault, things like that. But cancer experience can also be traumatic. But it's important to know that the studies that we have suggest that diagnosis of cancer, a treatment of cancer, can elicit full PTSD syndrome, but only in a minority of patients.



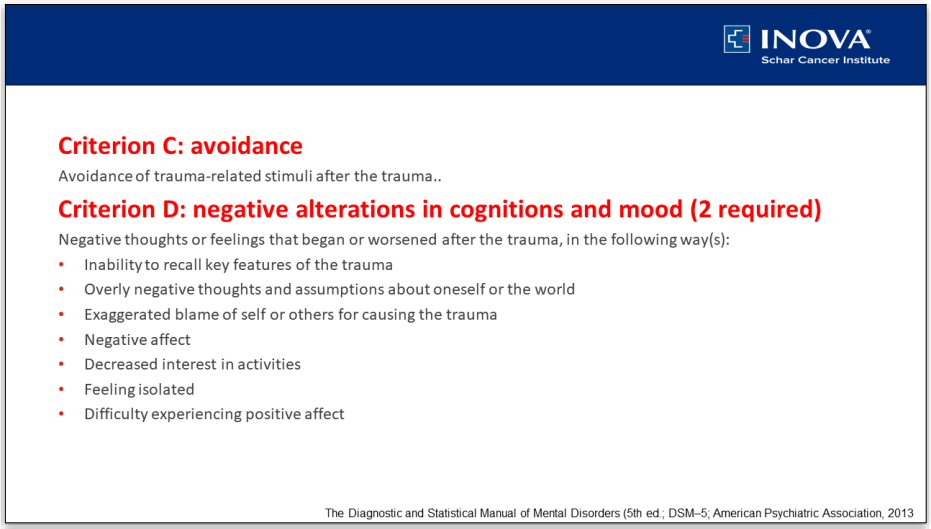
Most of the time the cancer experience itself doesn't lead to full diagnosis of PTSD. Nevertheless, even if you don't have a full diagnosis of PTSD, you only have some symptoms, what we call subsyndromal symptoms, they're very common and also associated with reduced quality of life. For example, we have studies that use structured clinical interview methods that reveal a mean prevalence, statistical prevalence for cancer related PTSD to be 6.4% ,and then 12.6% for lifetime PTSD diagnosis in cancer survivors. Which when we compare to general US population, it's actually almost double. Cancer clear clearly is a risk factor for PTSD. And if they have to summarize, set up how PTSD works, why PTSD happen, and this is probably too simplistic, but basically when the brain doesn't know that the trauma that you have is a memory.

Dr. Sam Lolak:

The brain still responding to it as if it's happening every single day as opposed to it being a memory. It doesn't become a memory until it's properly processed and given their proper place. So in psychiatry, we use the criteria called DSM-5 to properly diagnose mental health disorder, PTSD is one of them. I just want to give you an idea of the range of symptoms that would meet criteria for PTSD, and this is sort of the abridge version of it. So to meet a diagnostic criteria for PTSD, patients have to have symptoms, have to meet criteria for A, down to A, B, C, D, F, G of the symptoms in order to meet the diagnostic criteria.

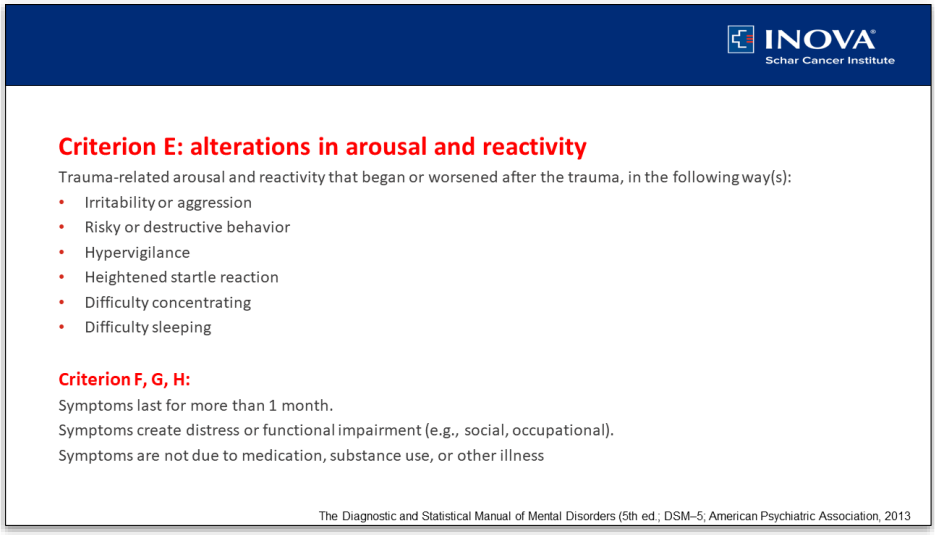


When we see the patients to go about properly diagnose them, you start with the first criteria, which is a stressor that the person was exposed to death, threatened death, actual or threatened serious injury or sexual violence. This one, it's hard to say whether cancer experience itself meet the criteria for this one all the time, but there's certainly a situation where patient was exposed to threatened death, actual threatened serious injury because of the cancer or the treatment. The next criteria you have to have what we call intrusion symptoms. Basically the brain is persistently re-experienced trauma in a number of ways. For example, nightmares, having flashbacks, having physical reactivities after exposure.

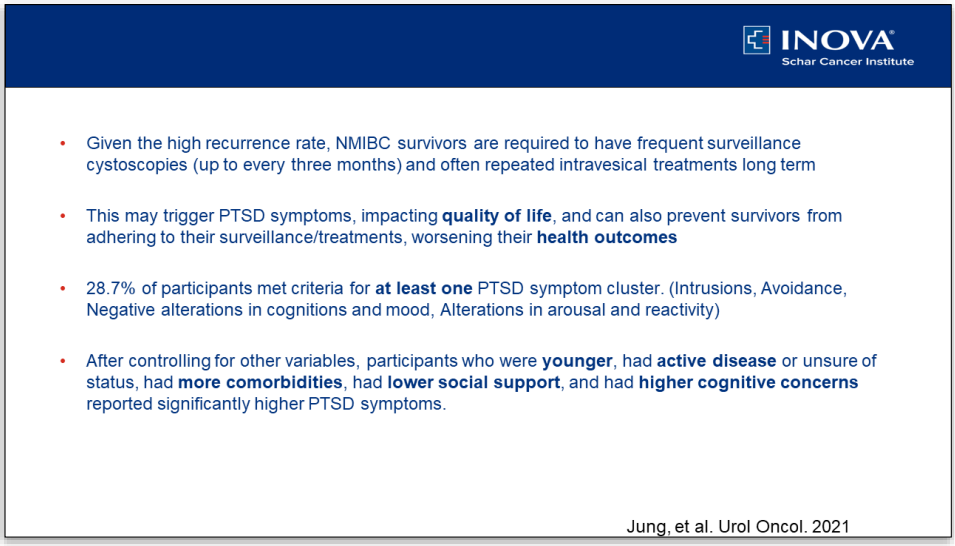


The next criteria is called avoidance. So you have a behavioral symptoms as a result of traumatic experience that you avoid seeing the things that remind you of the trauma, avoid of any stimuli that reminds you of the trauma. In this case it's the cancer experience. The next criteria is what we call alteration in cognitions and mood. And that includes having depression, negative affect, decreased interest in activities, inability to recall the actual details of the trauma. And this happened a lot in cancer patients where if you ask some cancer patients during the key event, they just went blank.

Dr. Sam Lolak:



And then you have what we call alteration in arousal and reactivity. We have what we call hyper arousal or hypervigilance, difficulty sleeping, difficulty focusing or having irritability. And then the next three criteria is the context of the symptoms that you have to at last for more than one month. It creates functional impairment or distress, and it's not due to specific medication, other medical illnesses or substance abuse. This is just to give you an overview of how to properly diagnose PTSD. But as I want to mention that, like I mentioned before, a lot of patients, cancer patients, even though they don't meet the full criteria of PTSD, they have only substance trauma criteria, it's still more than enough to cause a lot of distress, emotional distress, physical distress, and it interferes with function enough that they would benefit from support.



So what's relevant in terms of bladder cancer? Because we know that of the high recurrence rate, some of these survivors are required to have frequent test cystoscopies, right? Every few months you have to have that procedure and it's that same procedure, repeated procedure over and over that sometimes can trigger that memory, that trauma. And this may trigger some of the symptoms that I mentioned before, impacting quality of life. It can also prevent some survivors from sticking to their treatment or their surveillance because of their reactions that they have going into the doctor's office, having the same procedure, medication over and over. So that's why this may be relevant.

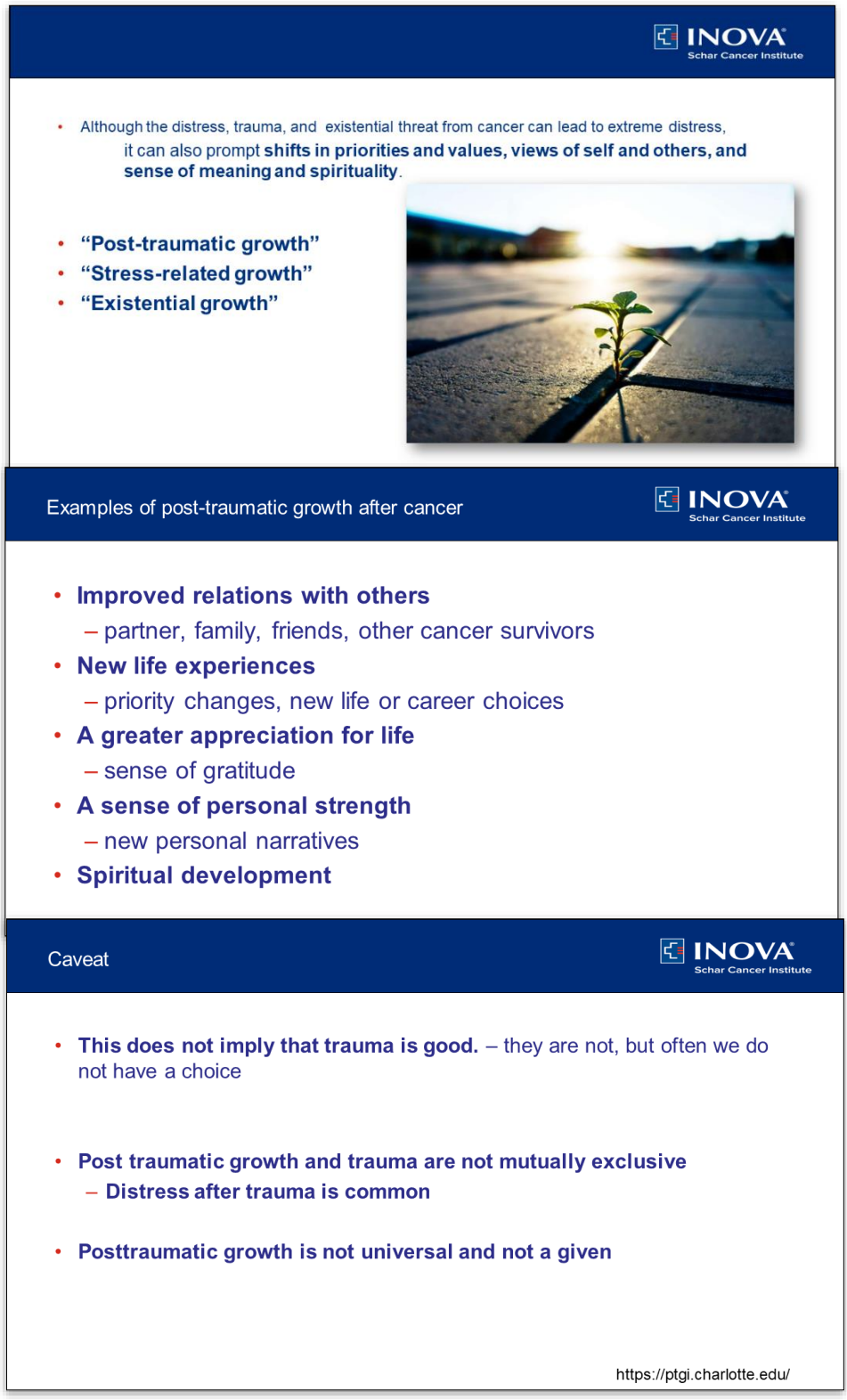
There's one study that showed that almost 30% of bladder cancer participants met criteria for one of the symptoms cluster. Not all of them, but one, either intrusions or avoidance or negative mood of hyper arousal. So that's pretty significant. And we know that younger patients or patients who have active disease or have more comorbidities, they have several medical psychiatric illnesses, may have lower social support or have higher cognitive problems associated with higher PTSD symptoms. That's their PTSD. But on the other hand, it's not all bad. Traumatic events are bad, but doesn't mean that everything that happened as a result of that is bad. Even though the distress, the trauma and the threat

from cancer can lead to extreme distress, it can also prompt positive shifts, whether it's in priorities and values, self views or sense of meaning and spirituality.

Dr. Sam Lolak:

We have a term for this. It's called post-traumatic growth or stress related growth or existential growth. For example, cancer patients sometimes will describe a change in several areas of their life. For example, improved relations with others, whether it's partner, family, friends, or other cancer survivors. They report enjoying new life experience because their priority in life has changed. They may decide on new career choices or focus. Report a greater appreciation for life or a sense of gratitude or a sense of personal strength, because they are able to develop that new personal narratives. So again, this does not imply that trauma is good. Nobody wishes cancer or traumatic events for anybody, and oftentimes we do not have a choice and people can have both.

It doesn't have to be either or. You can suffer from the effects of traumatic experience, but you can also grow from it. They're not mutually exclusive and it's not a given. Some people don't have that post-traumatic growth, and that's okay. That's sort of the part of my talk that has to do with PTSD and the anxiety diagnosis.



BCAN would like to thank our sponsors

for their support