

Stephanie Chisolm:

So, welcome to When Cure is Not an Option: Managing difficult conversations and treatments at the end of life, a Patient Insight Webinar from the Bladder Cancer Advocacy Network. Direct to consumer advertising often showcases advances in treatments for bladder cancer, with many patients that benefit from these new treatments. But unfortunately, not all options are curative, and may not improve patient's overall survival, or even their quality of life. And not all doctors or patients and their families talk about the services that could improve both the quality and quantity of life with patients that might have advanced or metastatic bladder cancer. BCAN is honored to host this important conversation to help you navigate and understand these difficult conversations and decisions and options.

I welcome Daniela Wittman, who is the Associate Professor of Urology and Social Work at the University of Michigan. And Elizabeth "Libby" Wulff-Burchfield, a physician who is a Professor of Medicine in the division of Medical Oncology and Palliative Care at the University of Kansas Health System in Kansas City, Kansas. So ladies, I'd love for you to turn on your cameras, and let's start having this difficult conversation.

Dr. Daniela Wittman:

Thank you very much for inviting us, and for giving us an opportunity to have this discussion with the participants. So, let me just...

Dr. Elizabeth Wulff-Burchfield:

We're so pleased to be here with you, thank you.

Stephanie Chisolm:

This is such a wonderful topic. It's so important, and we really can do a lot to make whatever time somebody might have left, and it could be years, to be the best time, by managing some of the treatments or some of the outcomes from their actual diagnosis. So I'm going to turn it over to you, and I'll fade into the background for now.

Dr. Daniela Wittman:

Thank you. And I'm hoping you can see my screen.

Stephanie Chisolm:

We can.

Dr. Daniela Wittman:

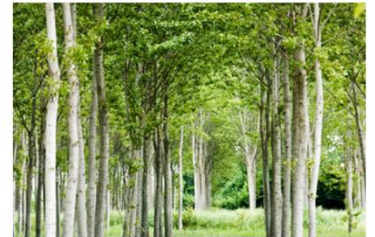
Okay. So again, thank you very much for being invited to be a part of this conversation. This is me. I don't have any disclosures. And I want to start out by recognizing that living with cancer is full of uncertainty. There are many ways in which you could say life is full of uncertainty, but in cancer that's especially true, because diagnosis of cancer brings about questions about what it means in one's life. Is survival an option? How long? Are there treatments that can cure the cancer, or at least prolong life? What are they like? Will they have side effects? Will they change the quality of one's life? So there are lots and lots of questions, and in talking to patients about their experience of living with cancer, they kind of live on two separate rails that move forward together. One is the fear of bad things happening, and the other one is hope that things will turn out well.

And when one learns that cure is not an option, that's a very important moment in that journey, because all of a sudden there is a certainty and it's a certainty that is not wanted. That is a certainty that nobody's wishing for, and it requires a lot of adaptation, because what does it really mean? Is it the end of everything? How much time is left? And is it time going to be good? And if one were to say, "Okay, no matter what it is, embrace it and live with it as well as you can," there's a process that most people go through before they can get to that place.

So, different people respond to the idea that maybe they will not live as long as they thought differently. It's, I think, fair to say that cancer brings about the question of loss and death. And, depending on one's age, depending on one's beliefs in general, overall health conditions, social supports, and relationship with the treatment team, different people respond differently. But I would say that most people experience feelings associated with grief and mourning, because even just the diagnosis is a loss of health and loss of imagined future. And so it ushers in, the diagnosis ushers in, feelings of loss.

When cure is not an option

- Living with cancer is full of uncertainty
- Fear and hope live side-by-side
- Learning that cure is not an option is an unwanted certainty
- What does it mean when cure is not an option?



Patients, families and physicians experience loss and grief throughout the cancer journey

- A cancer diagnosis ushers in thoughts and feelings about loss and death
- Different people have different responses to this possibility, based on their age, physical and emotional wellbeing, religious and spiritual beliefs
- Most people experience some feelings associated with loss – feelings of grief and mourning

Now there are all kinds of grief that a person can experience. Anticipatory grief can happen. For example, with a diagnosis of cancer, there's the anticipatory grief, "What is my treatment going to do to my body and to me mentally? How is that going to work?" Reactive grief is a grief that happens to something that's already happened. So when the diagnosis happens, we react. And then throughout the journey, there may be short, temporary upsurges of grief when the feelings about what's going on come to the fore.

Dr. Daniela Wittman:

Grief is a very normal response to loss. And so everybody should feel like, if they have an emotional response of grief and mourning to their cancer diagnosis, or any aspects of the cancer experience, that that is very, very normal. One of the things that's difficult about cancer is that it can be an ambiguous loss, because you really don't know what the future holds. Ambiguous loss and grief has been coined around soldiers who were missing in action and didn't return from the war, so that their relatives never felt that they could fully grieve them, because they still held out hope that they would come back. But I think this is a concept that's very relevant to cancer. Grief can become complicated. It can become complicated when it's difficult to get past some of the feelings that come along, and move forward from them. And it can become chronic, ongoing.

Here are some of the feelings that are associated with normal grief. Not everybody has all of them, some people have some of them, and everybody can look at this list and see what would apply to me? What do I feel? Do I feel sad? Do I feel angry, anxious, hopeless, helpless? Maybe hopeful? I may be comforted because I have good people around me. Or do I have a sense of a completion, because I've lived a long life and I feel like no matter what happens, I'm going to be okay. Any of those feelings can come up, they don't necessarily all come up at the same time, and they're all, a hundred percent, legitimate and normal, and anybody who feels them should feel like, "Yeah, this is what goes with cancer."

Types and forms of grief

Types

- Anticipatory grief – we know that loss is coming
- Reactive grief – reacting to a loss that already happened
- Short, temporary upsurge of grief (STUG)

Forms

- Straight forward/normal
- Ambiguous
- Complicated
- Chronic

Rando, Research Press, 1993

Grief and mourning are normal responses to loss

- Feelings associated with normal grief are
 - Sadness
 - Anger
 - Anxiety
 - Guilt
 - Hopelessness
 - Helplessness
 - Fear of the future
 - Uncertainty about how to manage new circumstances
 - Hope
 - Comfort
 - Sense of completion



We all defend against feelings of loss. So that's also a normal response. We all defend. Some of those defenses could be denial, like pretending this is not happening. Avoidance, like never wanting to talk about the subject. Over-optimism, this is sometimes problematic when other people react to us and say, "Oh, I'm sure there are really great treatments and you're going to be okay." How do they know? Deferral or delay. For example, somebody who may be diagnosed in the middle of a medical crisis may not be able to really deal with it until they get better from that medical crisis, and only then can they begin to cope with what they actually found out.

And sometimes, and now I'm talking about healthcare providers, sometimes healthcare providers defend against the feeling of discussing loss with their patients. That maybe somebody else's job to talk about it, so they don't have to. Now, I want to say that, I'm going to come to this in a minute, that both patients, family members, and providers, so all three, I guess, have these feelings when cure is no longer an option. Everybody has those feelings, not just the patient.

Dr. Daniela Wittman:

So I just want to mention that throughout survivorship, there are different times when people have feelings of loss. Obviously at diagnosis and during survivorship, this could be functional losses, losses of body parts, or it could be the way that one has to be in the world differently. Loss and grief are definitely a part when a recurrence occurs, and certainly during the advanced stages of cancer. And so certainly, it comes up when treatment is no longer an option.

So here is why both patients, family members, and providers have trouble. We manage separation and loss from the time we are very, very small. Little children have to learn how to separate from their moms and their dads to increasingly go out into the outside world. And I think any one of you who

Defenses against loss

- Denial
- Avoidance
- Over-optimism
- Deferral/delay
- Thinking it is someone else's job to talk about it

The normal and unique experience of loss and grief in living with a cancer

- Loss and grief at diagnosis
- Losses during survivorship
- Loss and grief at the time of a recurrence
- Loss and grief in the advanced stages of cancer
- **Loss and grief when treatment is not an option**

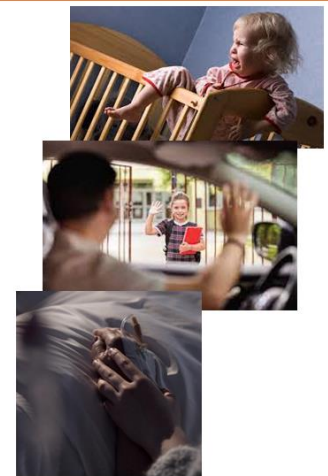
has children will know that children have to master that. That's because it's a part of attachment, a part of the human experience, and most beautiful part of the experience is attachment. We are attached to each other, we love each other, we rely on each other. And the price of having that kind of special, special relationship is that when that relationship may end, we experience feelings of separation and loss, and those feelings I described in a previous slide.

Previous experiences with separation and loss can help us understand how we react in any next situation. Somebody who's had a lot of losses may be either strengthened by them, and know how to cope, or they may feel overwhelmed because it's one too many. But everybody comes to the experience of loss when cure is no longer an option via their own template for how they're going to react. And if you think about it, the end of life is the ultimate separation and loss. And so people on both side of that relationship, whether it be the patient and family member, the patient and healthcare provider, or family members, healthcare provider, everybody has to face that feeling.

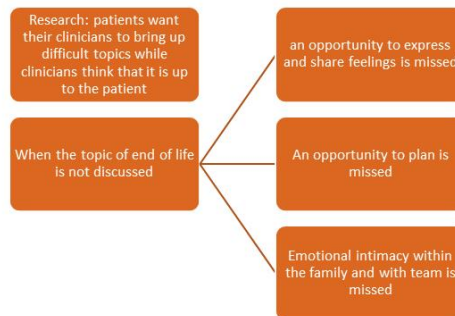
We know that those are very difficult conversations. Research has shown us that healthcare providers are not really very good at discussing it. And here I'm not talking only about physicians; it's true for nurses, it's true for social workers, it's very difficult for everybody to talk about something that is ending, where treatment is no longer an option, and people have to look at the other side.

And so, there's a tendency to maybe want to postpone it, or to not discuss it at all. But of course, when one doesn't discuss it, we miss the opportunity to express and share feelings, which actually when they are shared and expressed, increase intimacy and a feeling of connectedness, which both the patient and everybody around them finds really very positive. It's also a lost opportunity to plan. Some people like to plan for whatever they'll do while they're still living. Some people actually like to plan their funeral. And there's an emotional intimacy that can really enhance that period of time, and so it's very, very useful. And not just useful, it can be very enhancing to not avoid these difficult conversations.

Why is it so hard for physicians and patients and their families to talk about ending treatment?



Whose job is it to bring it up?



And now I'm going to turn over to Dr. Wulff-Burchfield to talk about palliative care, and its role in the context that I just described.

