Living Beyond Cancer

The Short and Long Term Psychosocial Effects of Cancer

Guest: Dr. Kaleena Chilcote

Lauren Hixenbaugh: Welcome to Living Beyond Cancer. Today we begin a series of podcasts created for cancer patients, survivors, and their caregivers. Living Beyond Cancer is sponsored by the West Virginia Cancer Coalition, Mountains of Hope and produced by the West Virginia University Cancer Institute's, Cancer Prevention and Control. I am Lauren Hixenbaugh, the program manager for Mountains of Hope and I would like to welcome you today.

The first topic in our series is the short and long term psychosocial effects of cancer. Today's guest is Dr. Kaleena Chilcote, Director of Psychosocial Oncology at West Virginia University Cancer Institute and Assistant Professor at the Department of Behavioral Health and Internal Medicine at WVU. We are thrilled to have you today, Dr. Chilcote. Our listeners may not know, but she is a pioneer in the field of psychosocial oncology, so we are going to start off today just talking a little bit about what is psychosocial oncology.

Dr. Kaleena Chilcote: Thank you so much for having me here today and hello everyone, if you are watching. Psychosocial oncology is just a term that describes mental health care for patients who have cancer; that is the oncology part. And then psychosocial refers to a wide range of symptoms, which often in my realm refers to things like depression, anxiety, sleep, appetite, maybe cognitive complaints, so things that you would see a mental health provider to address. But in some places also includes social work and other services that can help address things like transportation and financial services. And so it may vary a little bit from place to place. We are going to talk primarily about mental healthcare today in this talk.

Lauren Hixenbaugh: Great. So how did you become interested in this field?

Dr. Kaleena Chilcote: By accident. I am going to be really honest. I hated oncology in medical school. I did not understand it at all and it turns out, I think it just was not taught very well and so I knew I wanted to go into psychiatry and then had the opportunity to work with some patients who had cancer and worked with some real leaders in the field as well and was so inspired. I think it is an area of humongous need, which we are going to talk about a lot today. I think that will be a recurring theme. But it is an area where pretty much every patient could benefit and so there is just so much you can do. You can do more medicine, more therapy, you can focus on a certain set of symptoms, and there is a lot of opportunity to help people.

Lauren Hixenbaugh: Well we are really glad that you happened upon us in this field and we are really fortunate to have, I think the other day I heard you were the only one on the East coast.

Dr. Kaleena Chilcote: Well, I'm the only one in West Virginia.

Lauren Hixenbaugh: Okay.

Dr. Kaleena Chilcote: And maybe Pennsylvania, although I have trained some folks who do this, who just did not do the formal training. There is a fellowship available in psychosocial oncology at just a couple programs in the United States. So there is less than 10 of us getting trained every year, formally speaking, but there are a lot of people out in the community and in big academic centers who have been specializing in mental health care in cancer for a long, long time and know a ton. So we are working on increasing the numbers and hopefully trading programs.

Lauren Hixenbaugh: That is wonderful. So one of the terms that we often hear when we are talking about oncology is survivorship. What does that mean to you?

Dr. Kaleena Chilcote: That is a hard question. Loaded a little. I would say, I have moved around a little bit in my, in my time working in this field and it is often defined differently in different places.
So since I have been here in West Virginia, what I have found is that most of my patients would define themselves as a survivor when they are no longer considered to have active disease, they are not actively getting chemotherapy or radiation. Maybe they have been told that they have no evidence of disease at this time. So these are often people who are on maintenance medication, maybe hormonal treatment, immunotherapy, something where it is a consistent dose over a long period or who are getting surveillance labs or imaging. Meaning you come every so many months to get your imaging, just to make sure things are still good.

It is a challenging word to describe though, because in other parts of the country means very different things. And most of our national organizations have a much broader definition for the term survivorship. And in a lot of ways that means really anyone who has ever had a cancer diagnosis, regardless of where you are in your treatment course. And so for me, it is sort of in the eye of the beholder, if a patient identifies as a survivor, that is fine. And if they do not, that is fine. I am more interested in how we identify and why. And so I think I ask patients all the time how they, how they identify and where people feel they are in their course.

Lauren Hixenbaugh: That is great.

Dr. Kaleena Chilcote: Which is probably more important.

Lauren Hixenbaugh: Absolutely. So for those patients, how do you identify their needs?

Dr. Kaleena Chilcote: For patients that identify as survivors?

Lauren Hixenbaugh: Yes.

Dr. Kaleena Chilcote: So this is really become a big area of emphasis just in very recent years. We worked really hard to take care of patients who had cancer, who needed acute treatment right now to save their lives. And really only in the last five, 10 years have a lot of people been putting energy into thinking about how we take care of long-term needs because cancer now is a long-term illness. It can be a chronic illness just like diabetes.

Lauren Hixenbaugh: And we have a lot more survivors than we ever have.

Dr. Kaleena Chilcote: Exactly. In some ways we do not have a lot of great science behind how we address the needs of survivors and we are kind of making it up and getting data as we go, which can be kind of exciting if you choose to look at it that way. But mental health has become a big push in a lot of national organizations including credentialing bodies, so groups that tell hospitals they are allowed to perform certain kinds of treatment for cancer. They are saying you have to pay attention to people's mental health now too. So that's been nice because it's forcing programs to screen, to ask every patient how much distress do you have and then try and figure out what to do about that. So that has been awesome because that is on a national level and even internationally in some places.
We're getting people sent to us now who have been screened by other doctors or other providers to help figure out-

Lauren Hixenbaugh: This is sort of seen as an unmet need?

Dr. Kaleena Chilcote: Oh absolutely.

Lauren Hixenbaugh: Okay.

Dr. Kaleena Chilcote: Yeah. Some places more than others. Even here in our own state of West Virginia, there are places like Morgan town where there are providers, there are a lot of places, that are not providers. I have patients who drive five hours within the state of West Virginia just to get here and so that is a horribly unmet need that we just do not have the bandwidth to catch up to at this point. We are working hard though.

Lauren Hixenbaugh: That was my next question. How do we address that? How do we start working on that?

Dr. Kaleena Chilcote: I think that is a big question and a lot of people probably smarter than me are trying to figure out. But I think part of it has really been the importance of having our colleagues pay attention to mental health needs and other things that contribute to distress. I am talking about mental health, but things like your physical symptoms and trouble with transportation and financial stress and trouble getting the food you need, all of that stuff really factors in to distress. And so having our colleagues get educated about what we should be asking and then what we do when someone is having a problem has been really important, especially in areas with rural populations. I cannot see everyone and so I am really relying on other people to help tell me who is the highest risk and who needs the most help right now.
But in the same way, we're trying to pay it back out and provide some education. Here we have a number of projects that we're working on right now, trying to get going a little bit to provide more education about mental health needs in particular, so that people in the community, whether it's your primary care doctor or your oncologist offsite or someone else will have more in their tool bag to help when we're not able to do that.

There are other groups though that do address mental health needs in cancer. You know, there are lots of national organizations and websites and most cancer types have specific websites that you can go to and get resources and potentially be hooked up with peers. And so those are things that we can sort of help people get guided to the right resources too.

Lauren Hixenbaugh: And you mentioned the oncologist and the primary care doctor. I have read a little bit and there is some frustration between kind of the linkage there. Patients aren't really sure, they are kind of in that middle ground, and so how do we work on that linkage and get them the services that they need?

Dr. Kaleena Chilcote: Yeah, I think this is a problem everywhere. It is even more of a problem when folks are traveling a great distance for their cancer care. Your primary care doctor is quite far away, not in the same system, cannot read the medical records through the computer. And patients complained to me about this pretty frequently actually. It is a problem. What I would say is we have to be our own advocates with our physicians, because no matter how great your doctor is, there are time constraints, there's communication issues, there's all sorts of other things that they're also having to work against. So as a patient, we really need to say here's my concerns. We need to ask all of our questions. And if we are worried about communication, bring it up. People are worried about offending their doctors sometimes. I hear that a lot.
If you feel like the communication is not good, I would just say, I am worried that it does not seem like we are all on the same page. What should we do about that? And they cannot ignore that kind of blunt question. And it is still, polite and respectful and that is not going to offend anybody. So I think advocating for yourself in that way is something we all just need to kind of find the power to do or bring a really good outspoken family member or friend with us. I do have patients who will record parts of sessions with permission from their team or take a lot of notes and I think that that is helpful for some people. The other thing that I have encouraged some people to do is, if you're worried about that, you can ask your doctor, I want some of this stuff in writing, can you write down that last thing you said and give that to me with my paperwork and the chances are they're going to agree to that and then you'll just have it in writing and even you can take that to your oncologist or vice versa and sort of carry that information back and forth if you need to.

Lauren Hixenbaugh: That is great. I think it is important for folks to advocate for themselves, not just in this field but in general, but certainly advocating for yourself is very important. So for the folks that are coming to see you, how do they get there? So we are kind of talking about the oncologist versus primary care doctor, is that a referral from either one or both? How does that work for them?

Dr. Kaleena Chilcote: I see patients for a lot of reasons and so that may determine how they get to me. The most common things that we see for in our program are depression and anxiety, which is probably not surprising to most folks who are listening to this. Depression and anxiety are very, very common in our world at this point. But they are also much more common when you have cancer. Depending on your cancer type, you may be three times as likely to be depressed or five times more likely to be depressed than someone without that kind of cancer. So those rates are really increased. But we also see other things. We see people with sleep issues every single day. And I see people for appetite issues. I see people for hot flashes due to their hormonal therapy for their breast cancer. So there are a lot of

things that might bring somebody to our door.
Most of our patients are referred by their oncologist or one of the nurses on the oncology team because they've noticed something. They have said, gosh, it seems like this patient is a little anxious or depressed or not sleeping. And then they will talk with the patient about it and make sure they are okay to come and see me. It is not something you would ever be forced to do, but it is an option that's there. We also have, you are welcome to refer yourself to us, which I think that sometimes people are afraid to do, to say, I think I need help, but you know yourself better than anyone else. And I think our oncology teams only get to see a little piece of what you have got going on in your life and what you are struggling with. And so if you are feeling like you are having a hard time, it's absolutely appropriate to say, I would like to meet with someone.

Lauren Hixenbaugh: Maybe they do not even know why they are having a hard time. So I think that question for them is important too, to come to you and say, I need help, but I'm not really sure what I need help with. And that is great.

Dr. Kaleena Chilcote: Yeah. Well, and people think that they can only come and see us for depression or anxiety, but there are a lot of other symptoms, irritability, other things that sort of can creep in and become problematic. And that is all linked to our mental health. So all of those things would be appropriate.

Lauren Hixenbaugh: And I guess this is kind of a side question, but I am going back to unmet needs here. So if people are talking with you and they talk about some unmet needs, maybe they do not realize that they have unmet needs, like transportation or things like that. Do you have a system for referring people for things that they might need that they do not realize they need?

Dr. Kaleena Chilcote: Yeah, absolutely.

Lauren Hixenbaugh: I hope I am making sense.

Dr. Kaleena Chilcote: Yes. Yeah. So you know, mental health care, as I said, is not one thing. A lot of things go into our mental and emotional wellbeing and that includes things like, how good are our relationships right now? How are we feeling spiritually? How are we feeling physically? If it's incredibly challenging to afford the bus ticket just to get here, that's going to make everything else more stressful. And so we talk about all of that, especially in a first visit, we go all sorts of things that might be part of why someone is having stress or depression or sleep issues. And so our plan is not always just medicine, which I think is what people think when they come to see me. That's what they're going to get. I may not even give a medicine to someone.
It may be that therapy is the most helpful thing. So psychiatry, I am a psychiatrist, meaning I am a medical doctor. I went to medical school so I can prescribe medicine just like your oncologist or cardiologist. There are lots of different people who are service therapists though who can do talk therapy. So you may get that from a psychiatrist, but it may be a psychologist or a counselor or a social worker. Therapists are present in most of our communities here in West Virginia. They may not specialize in cancer in particular, but there are lots of talented therapists who can help with things like depression and anxiety. They may need you as a patient to tell them a little more about your cancer, in

particular, but they're there and can be helpful. But we also work very closely with lots of colleagues like palliative medicine, our different pain teams here in the community, physical therapy and occupational therapy, our sleep medicine colleagues. I send people for sleep study almost every day.
We work very, very closely with our social workers. And so here on our Morgantown campus we have a team of very talented social workers who, in particular, are helpful with things like transportation and financial stress and how to get your medicines coordinated and that kind of stuff. So sometimes you may have all of us on your team by the end. Sometimes it may just be one or two, or maybe I just give you a medicine and you walk out the door. But it is all about working together to figure out what each person thinks will be helpful.

Lauren Hixenbaugh: Overall health.

Dr. Kaleena Chilcote: At the end of every appointment I ask whoever I am with, what do you think would be most helpful for you, because we all have to work together.

Lauren Hixenbaugh: You mentioned psychological and spiritual wellbeing. You want to talk a little bit more about that?

Dr. Kaleena Chilcote: Spirituality is a really important part of our lives that we do not talk about. It is sort of like sexuality, there are things that still somehow are taboo, I think, especially for physicians. In medical school and residency, it is actually fairly rare to get training on how to talk about some of these topics and so it feels awkward. We talk about them all the time in our clinic because these are important parts of our everyday life and whether we talk about them or not, they are still there, and they're still contributing to how we do. We think about with spirituality, we think about religion a lot of the time, but I think it is actually a much broader topic than that. And so I would say spirituality is however you find meaning in your daily life. So what gives you meaning as you go through your day in your relationships, your work, however you spend your time.
So that may be a faith in God, but it may be something totally different and when you find peace with that, our emotional wellbeing usually gets better too. And when we feel stressed about that or our faith is, we are feeling questioning of our faith, that can really impact everything about the way that we go through our day. So I ask people about those things as well. And we, here on our campus, have a fantastic chaplain, Amanda Hill, I refer to her pretty regularly as well, and offer her services too, because that is part of our emotional wellbeing too.

Lauren Hixenbaugh: Certainly. I can see how that would be a big part of what you do. People questioning and finding peace and that sort of thing kind of wraps all into that.

Dr. Kaleena Chilcote: Well, lots of, why me. That's a question 100% of people ask, why did this happen to me? And so our spirituality, how we find meaning in our day is a big part of how we kind of think through that question. Sometimes we need some guidance. I may not be the right person, but your pastor might be. If that's what helps, that's what helps so we have to think about that.

Lauren Hixenbaugh: Is there anything else that you feel like you want to talk about? Go over today?

Dr. Kaleena Chilcote: No big topics. I know one of the questions that you had posed earlier was about how do we determine if someone needs care. And what I made some, a couple of notes and what I actually wrote was, can I say everyone needs care. Is that allowed? I actually think cancer is a very, very stressful, whether you have the earliest stage, simplest thing that everyone says is cured and you are never going to have to think about it again or you have stage four cancer. Everyone finds this very stressful, it disrupts life. And one of the biggest things that cancer does is it takes away a lot of our control. So we used to really have a grip.

Lauren Hixenbaugh: Control in all facets of your life.

Dr. Kaleena Chilcote: Yes, we had a grip on how things, how life was supposed to go and now it's totally different and no one is supposed to just take that and say, Oh yeah, I'm fine. That is not how we work as human beings. And so I actually think probably a lot more patients should have mental health care as part of their care than even what we can do here in a really pretty well-served place. We have lots of resources and so there is never a patient that I have said, Oh, this person did not need anything. There is always something that we can be helpful with. So if a patient, any patient says, I think I might benefit, then you would. That means to me that you would. So if you have any question about whether it be helpful, you should just come in or see someone in your community. Because to me that means there is something, there is something going on.

Lauren Hixenbaugh: So just to pick up on what you said last. One of the questions that I personally would like to know is, I have a close family member that has received cancer treatment and they may not realize that your services would be helpful. How do we get our loved ones to benefit from your services? Or how do we get them there?

Dr. Kaleena Chilcote: That can be a really tough question because that depends on people's personalities. We all have kind of reluctant family members sometimes and I hear that from people a lot that they will say, my wife has been trying to get me to come here for six months. What I would say is that if we kind of take a step back, some of ... I've just already told you that depression, anxiety, sleep issues, they're all so, so common. And so where do we say this is the line where it is a problem and where is it normal? I think is a question I get a lot. And so what I would say is as a family member or as a caregiver, I would be watching for when these symptoms start to impact how well someone can get through the day.

So if depression or anxiety is to the point where someone's not taking care of themselves, not getting up, getting dressed, showering or bathing, not wanting to take their medicine. You maybe notice things they always did. Like they always used to walk the dog every morning and now they're not doing that. Those kinds of changes in daily life or somebody's unable to go to work because they just want to be in bed or they're so anxious when they leave the house or unable to sort of participate in relationships the way they did. Maybe you notice that your friend is starting to cancel all of the times when you set up plans to get together. So when it is really starting to change daily life, that's when I think it's time for people to really intervene. And I am all about sort of being open and honest and communication of course.

So I think what tends to be most helpful is just an honest conversation where maybe you point that stuff out in a gentle way. So say you know, Hey Sue, I noticed that you've canceled our last three times we

said we were going to get together. I am worried about you. What's going on? Because people often are afraid to bring up certainly what they are feeling inside, and especially with loved ones. I hear all the time, every day someone says, well I feel guilty that this is affecting so and so. This is affecting my wife. And so I do not want her to know how bad it is because then she is going to feel bad. And so that applies all of our loved ones. Or people say, if I tell them I feel this hopeless, they are going to think I am not fighting anymore. They are going to think I gave up and I did not give up. I just feel like crap.
So people have all sorts of thoughts in their head that make it harder to be really open and honest about the emotional part in particular. And so I think sometimes it is easier to not go to the emotion and to just say, I noticed this about something you are doing. It is about the behavior. And so I would say it in psychiatry speak, but it's a change in how that person interacts with you that you can really point out. Because we do not as family and friends know what someone is feeling necessarily. I think that is actually true if there are providers listening. A lot of the time patients tell me they do not want to admit this stuff to their doctors. If I tell my oncologist, I think this is not going to work and I am really worried about it, they think I do not trust them. They think, I do not think they are a good doctor. So why would I say that to them? And that is not what you are saying. You are saying, I am really struggling to find hope that gives me through my day. And that is a very different thing. So I think it is just pointing out some of the things you have observed and saying, should we do something about that? You know, what do you think would help? How can we get you back to who you are? And that tends to be the most successful.

Lauren Hixenbaugh: Wonderful. I think that is very helpful for folks to know. And as we start to wrap up today, I kind of want to go back and touch base on a few things that we have talked about. So one of them, and you sort of just covered this, but who should seek your services?

Dr. Kaleena Chilcote: Again, it is sort of my, I think everyone could benefit. So if you are sitting at home and thinking some of what you said sounds, rings true to me. I am having a hard time with my mood, with motivation, with anxiety, with sleep. I have noticed that is impacting my day or my husband's day. I think that's, that's the time to say let us get some help. I think we tend to wait until it is too late. And so today is a good day to do that.

Lauren Hixenbaugh: I like that. Today is a good day.

Dr. Kaleena Chilcote: It's a good day. So you know, there are not concrete criteria to see any mental health professional anywhere. If you want to, we are here and we will see you. And that is true everywhere in the country.

Lauren Hixenbaugh: And let us remind folks. How do they receive the services?

Dr. Kaleena Chilcote: So here in Morgantown, it's the simplest, obviously because we have a big team. So the best thing to do if you see an oncologist through the WVU system is to tell your oncology team. It does not have to be your physician, any nurse, one of your navigators, anyone on your team, if you would let them know you'd like to come and see us in the clinic, they can put a referral in or call us. And most of them know how to do that. And so that is the simplest thing. There are resources available in the community. Again, maybe not quite as specifically cancer related, but there are lots of really talented psychiatrists and different kinds of therapists in the community here in West Virginia and so I

again would ask your oncologist if you are in one of our other areas of the state and ask them if they have someone that they like and would recommend.
The same thing as true for primary care doctors though. Often if you say, is there somebody that you like that you would send someone you too often they have somebody in mind and so that that can be helpful. There are some websites that can help people find services. I have absolutely no affiliation, but there is a website called Psychology Today that is a nonprofit and available all over the country that you can put in your zip code and insurance information and therapists and psychiatrists can actually go on and put a photo. They can put a profile about themselves and so that can be a way for some folks to find a therapist in particular, if you are outside of our community right here.
The other option is always to call your insurance. If you are in another area and you do not have somebody you really trust, your insurance will say, here is these three big clinics in your area that we will cover you if you go there. And so that can be the other resource that is most reliably helpful.

Lauren Hixenbaugh: Okay. So is there anything, if folks did not get anything out of our conversation today, what is the number one thing that you would want them to know?

Dr. Kaleena Chilcote: Well, I think for me the big takeaway should be that saying you need help is okay. I think, especially here in West Virginia, I see a lot of people who say, I should be able to get through this on my own. And I do not know who made up that rule, but this is very stressful and this is very hard and there are lots of people here to help.

Lauren Hixenbaugh: Life changing.

Dr. Kaleena Chilcote: Yeah. And so why not take advantage of the resources that are available? You would not see your oncologist because you should be able to cure your cancer. This is an illness. Depression is an illness, anxiety is an illness. And it is something that's treatable. So I hope that people take away that. This should be a part of everyone's treatment, so if you need help, just ask for it.

Lauren Hixenbaugh: Great. That is great advice.

Well, to find out more information about living beyond cancer and the West Virginia Cancer Coalition, Mountains of Hope, you can check out our website, moh.wv.gov or you can visit WVUcancer.org for more information on the West Virginia Cancer Institute. You can also look at our Facebook support group for folks that are caregivers, survivors, or family members. It has entitled the same, Living Beyond Cancer. I would really like to thank you, Dr. Kaleena Chilcote, for coming today and talking to us and bestowing your knowledge upon us.

Dr. Kaleena Chilcote: Thank you for having me.

Lauren Hixenbaugh: Just a reminder, Dr. Chilcote is the Director of the Psychosocial Oncology Department at West Virginia University Cancer Institute. We thank our listeners for joining us today, and we hope that you will continue.