**Speaker 1** 00:02

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**Speaker 2** 00:20

Welcome to the cancer assist Show. I'm your host, Dr Bill Evans, and today it's my pleasure to talk with Dr Karen Zhang, who's an assistant professor in the Department of Psychiatry and Behavioral neurosciences. Good to see you again, Karen, nice to see you. Dr Evans, it's been a while the last time I think we're talking during COVID and we were separated by a great distance on a boardroom table somewhere, but it's nice that we're past that and we can have a conversation about a topic I think a lot of people will be interested in, because after you've been treated with cancer, a lot of changes happen to yourself and how you perceive yourself as a result of the treatment, maybe particularly so with some cancers that physically change you. Breast cancer, maybe a mastectomy or amputation of an extremity, for a sarcoma, various things like that that are really change how you look at yourself and feel about yourself. And so it's such an important topic, because I think a lot of people maybe just kind of fall into a depression and are anxious about how they appear, don't want to socialize, don't feel comfortable at work. There's a whole need to kind of rebuild themselves. And I think this has been a particular area of your interest and and I think research as well, and so I think an important topic for people to to grasp. So maybe just start at the very beginning of how, what? How do we sort of think of ourselves? What's the sort of conceptual framework that we have in our minds? Maybe we don't have it well formed in our minds, but that researchers think about the components of our of our self identity?

**Speaker 3** 01:59

Yeah, yeah. This is a topic I'm very passionate about, because I see it in almost all my patients. But I have to say, agreeing to do a talk or podcast about this is it's a bit overwhelming, this idea of rebuilding an identity, something that you spend your whole lifetime forming, and how can I do that in half an hour an hour so and it can also get very existential, like, what is the self? What is identity? But I think if we really break it down into a very practical way, there are certain elements that make up who we are, and we think about that in terms of when we think about who are you, there are different areas that we identify with, and this includes how someone feels, they're functioning, physically, cognitively, their physical appearance, their social roles, of like, what kind of relationships you have, what roles you play, and also the type of work that we do. So this framework, which encompasses this, these six parts, so again, the physical, the cognitive, I forgot the emotional, the roles, the work and also our appearance. These six parts really form a sense of who we are.

**Speaker 2** 03:13

And I guess each and every one of those six parts can be disturbed by going through a cancer treatment or having a diagnosis of cancer. So should we just sort of break them down, one at a time, and think a little bit about both the impacts of the of the cancer treatment and how you rebuild afterwards? Yeah,

**Speaker 3** 03:33

yeah. So I'll start with the most visible part, the physical appearance. Hey, and I think for many people, that's difficult. The loss of hair changes to weight, whether it's weight gain or weight loss, and people often say they just look different. Skin is different. They they don't feel like themselves. They don't look like themselves. And especially, we had surgery certain certainly that would change your appearance. I think what can also be distressing is even for people where their appearance does not change. So sometimes when patients will say, you know, people tell me that I look good, I don't look sick, but that comment actually can be really triggering, because it can invalidate everything that they've gone through and how much they had to go through because they're sick. So the physical appearances is a tricky one. It's all about a change, but sometimes it can be tricky. Even if there's not a change, there's something about the internally, we feel different, and externally, we're very sensitive about how that's being perceived.

**Speaker 2** 04:36

And for some, some types of cancer, let's say breast cancer. It really does, I'm sure, have a big impact on how woman perceives herself, her beauty, how she relates to her, her partner, and intimacy and so on. Those must be particularly challenging issues, absolutely,

**Speaker 3** 04:57

and I have many. People tell me that they feel guilty because they don't wish to be vain, or they're very thankful and grateful that, you know, they're able to get treatment and do better physically. But it, course, is distressing when there are changes, especially changes to our body that's associated with a feminine identity or a sense of who we are. And it's not just the way that we look, it's how we relate to others because of the way that we look. So as you mentioned, Dr Evans, like the intimacy part can be impacted, the self confidence can be impacted. So something like breast cancer, absolutely and for many men too, there's oftentimes a lot of muscle loss because of treatments and just low energy, and that can be distressing as well for the masculine identity. So

**Speaker 2** 05:45

maybe we can take these one at a time if we're talking about rebuilding. So on the physical side, I suppose there's a certain amount of physical rebuilding we can do, because there is possible with breast cancer, for Reconstruction and so on. It's not perfect, because it leaves scars and doesn't look exactly the way mother nature created it, but nonetheless, it may help with the improvement in one's body image and make it easier for one to relate to others, but many other aspects of it, how you look, the hair loss and factors like that, are a little more challenging, it would think, too, in this kind of rebuilding of self identity on the physical side,

**Speaker 3** 06:26

absolutely. And I think this is where Cap has been really important in terms of having wigs that people can loan. And I think you know doing what you need to do to feel a little bit better, whether it's wearing a wig that makes you feel more confident, or prosthesis, or whatever it might be. I think those are all very positive things. I think this idea of body image, I can give a whole other hour or five hour talk on but I think one thing I do want to leave with people is thinking about not just the body appearance, but thinking about the body's function, and can we learn to find appreciation for that. So what I mean by that is thinking about how much the body has gone through and going through the treatment, and how it carried us through all those different hardships and difficulties. Can we find a moment to appreciate what it has done for us and maybe not be so harsh on how it may look so the body may not look at its best or the way that we wish it would, but it's done a lot for us, and it's fine finding that appreciation for that function

**Speaker 2** 07:29

that's an interesting thing is to think about that you should show appreciation to your body for carrying you through a Different, difficult journey. Okay, so that's some of the physical side. And I guess in terms of programs that are out there to help support people, I you know, the cosmetic industry has a look good feel better program, and others have similar sorts of programs to help people, particularly women with cosmetics and so on, is to feel and look like they're feminine again,

**Speaker 3** 08:04

absolutely yes, look good. Feel better. Is an excellent program. Pink pearl, which is for women 40 and under, also has excellent partnerships and workshop. I don't know if it's an exclusive partnership. I know, for example, Sephora has a program that's all about helping people who've gone through cancer to feel good. So clearly, there's something here. If these big companies are recognizing that this is a huge area of need for many people that you know, if you're worried about how you look or you feel sad about the changes, you're not alone, right? And there are many resources that can help you with that as well. So

**Speaker 2** 08:40

let's move to the emotional side, because that sort of follows kind of logically, and I understand from the literature that a high percentage, maybe 50% of individuals after a cancer diagnosis, will have depression and or anxiety. So it's very common to have emotional changes as a result of the cancer. It's quite understandable. How do you kind of rebuild on that particular dimension of self

**Speaker 3** 09:12

identity? I think in terms of emotional changes, there's a couple things. There's some people that may have experienced depression anxiety before cancer, and they may see that it has come back, or they're experiencing it in a new or maybe more intense way. And then there are folks that never, or they would tell me that they've never experienced depression or anxiety and and they're really struggling with understanding again, this new person that's really struggling with crying at the sort of anything that may show up, any TV show, or finding that their emotions are bubbling at the surface. And what's distressing for individuals like that is not just the experience of the distress, but it's that they never reacted in this way before. So this is new and is threatening to a sense. Who they are. And I would say that before we can apply any fixes, we have to first understand what are we feeling. I think for some folks who've dealt with depression anxiety, they may understand where to find resources and what helped them through the last time, and those same coping strategies can be very helpful again. I think for some folks, where this is new, these are new feelings. I've never felt this intensity of fear before. I would say, first, maybe we have to understand what's driving that right. And it can always be helpful to talk to someone about what you may be going through so that you can make sense of it. And it could be that you you do have the coping strategies to deal with it, but if we don't understand what we're worried about or why we're feeling very down, it can be hard to apply a fix. So I do want to highlight that for our Cancer Center at jarovinsky, but also many cancer centers, there often is a supportive care psychosocial oncology team that is meant to help with that emotional recovery after cancer. In

**Speaker 2** 11:02

your presentation about rebuilding self identity after breast cancer and the concept of being curious about it, it's almost like detach yourself a little bit and inspect yourself and what you're going through and be curious as to why things have changed, why you're feeling a certain way, kind of be a little more thoughtful about it, or,

**Speaker 3** 11:27

yeah, self aware. It's really great that you kind of highlighted that that's actually one of my favorite words to say, is, can we be curious? And the reason why I say that is I notice many patients suffer because they hold on to this idea of who they are, who they were, and everything that's different or new they will compare to how they used to be. And the change is what brings that suffering, and there's a lot of judgment about that, is that I shouldn't be this way. I should be exactly like the way they used to be exactly but when we think about all the changes that have happened through the cancer journey, it makes sense that someone would be different, and different doesn't mean bad or worse or not as good as before, it just means different. And I like the word curiosity, because it means can we not be judgmental about what is different, but just be curious about, what are things that seem to make you happy or bring you sadness, rather than thinking that I shouldn't feel this way because that shouldn't is what brings on that suffering or more of that distress.

**Speaker 2** 12:32

So, and you had the comment too, of it's okay to not be okay. Yes, comfortable with the fact that you're not feeling happy all the time, or comfortable in yourself, or that your emotions are going up and downs? Yeah,

**Speaker 3** 12:51

yeah. And I think I talk about that when we deal with emotions, it's really about not trying to change it or push it away. So a lot of times we feel that we have to be positive, and that's a really tall ask, considering how much a cancer journey can be taxing and difficult, and then you have to be positive on top of that, that's just unrealistic. And this idea of being okay with not being okay is can we just reflect on that we can be sad and allow room for that sadness, rather than try to change it and push it away. And if you give it room, it actually can go away a little bit faster. And I do want to dispel the myth that if I allow myself to get sad, that means I'm going to get depressed. And I will say that depression doesn't happen because we're sad. It happens because we don't allow ourselves to be sad while we judge ourselves for that sadness, and that brings on shame, and that's what really carries on depression.

**Speaker 2** 13:48

That makes sense when you explain it that way. I kind of like that. It struck me as you were talking about that, that you know, cancer treatments have changed a lot over my career, and for the most part, early on, treatment courses were relatively short, and so the journey of cancer was was relatively short. You know, the chemotherapy we had didn't work very well, so you didn't have a lot of exposure to it. Now, with some of our more effective regimens, particularly in the immunotherapy that go on for years. So it's a very different journey. So that the impact on your self identity, because you're you're much more likely to view yourself as being a patient longer because you're going to the cancer center every month for two years or more to get active treatment. And so the whole self identity could be changed and more fixed in a state, whereas in the past, it was relatively a brief encounter with the treatment. In. It was ineffective and and that's why it ended in a shorter time frame. But it does mean that the impact on self is is different now than it was years before, and could be a greater issue to try and self correct or rebuild as I'm thinking about it with you now, so and so, in terms of things like we've talked about emotions in the physical side, one of the aspects that you hear a lot from patients, I think I heard first from breast cancer patients, that may be more particular to them, is this whole impact on cognitive function. That's that cognitive function changes that treatment, in some way, is affecting how the brain works in this concept of brain fog. Can you talk about that for our listeners? A bit. I

**Speaker 3** 15:54

would love to talk about that so I don't think there's enough attention or focus on how distressing it can be when we notice cognitive changes. So I would say, certainly for breast cancer patients, but also for many patients who've gone through like a stem cell transplant or kind of very rigorous treatments that does have impact on cognition. So I would say that this is still an area that is not well understood, but it's well documented. So many patients would say that after treatment, they notice they cannot recall things as much they may have difficulties finding words or just remembering details, and why that's threatening to that sense of identity, to identity and self is, if you're someone who's always maybe took pride in your intellectual abilities, because that's really what helped you, let's say, do well at work. Or you're someone who's always very thoughtful, and you manage everything in this household, and you're used to multitasking, and then after you go through these treatments, you can't do all these things that make you feel good about yourself and your cognitive ability that can be really hard to that sense of self is feeling like I'm not as smart or as capable as the person that I used to be, and that's where the threat is. So

**Speaker 2** 17:12

how do you rebuild from that? Yeah, that must be a real challenge. You know, I heard more about brain fog in the context of COVID infections, because a lot of people experience brain fog and a very variable duration. I have a friend who was doing very well at school and then got brain fog and then just couldn't take in information, store the information, do examinations for a while, got better, but it took a year, and then gets an infection, with a minor infection, and then brain fog comes back again. So it's really discombobulating to experience this kind of phenomenon. It must really pull your self worth down, because we so much rely on our cognitive function to think about who we are

**Speaker 3** 18:09

absolutely yeah. So I think maybe two aspects to think about when we think about rebuilding that cognitive ability. The first thing is, we know from the literature that there is a period of time that requires recovery for the person to regain their functioning, and usually that's about the two year mark for breast cancer patients to really kind of regain their cognitive ability. Also within that two years, usually people are able to find strategies to compensate for difficulties, so we don't actually see a disruption to functioning, so a person actually can function as well as they used to, even though they may notice a difference in the way that they're recalling information or retrieving information. So usually we say allow some time for the body and the mind to do its natural recovery from the treatments. The other thing to be mindful of is actually anxiety, so cognitive functioning or difficulties with that, it has shares a lot of overlap with anxiety. So when we start to become anxious about our inability to remember something that actually makes her memory worse, yeah, and then sometimes that's actually a tricky thing for us to tease apart. Is this really anxiety that's driving some of these difficulties. Because anxiety can it can make someone have difficulties, concentrating, problem solving, decision making, which all mimics cognitive difficulties. So I would say that if someone is experiencing cognitive dysfunctioning or problems and they're worried about it. I would recommend some treatments, actually, to address the worries, because if we can take the anxiety away from that usually helps with the recovery a little bit

**Speaker 2** 19:50

better. That's good advice. We're sort of working our way through the six components of self identity, as though we've touched on 50. Physical and cognitive, emotional. What about roles, particularly social and vocational roles, two different elements there. How do those change in the course of the cancer journey? And how do you rebuild your roles?

**Speaker 3** 20:16

Yeah, yeah. Good question. Now, first go through the social roles. I think that seems to impact everybody. So cancer does change relationships. Many patients tell me that they feel perhaps disappointed or hurt that that childhood friend or that friend of 20 years didn't show up for them the same way that they would hope or expect, but someone they met in the waiting room at the cancer center has turned out to be a closer support than that friend of many, many years. And so we start to notice that who we consider to be a good support can change during the cancer journey, depending on our needs. And that's not always a bad thing. It doesn't mean it's staying this forever, or that childhood friend is someone that you now need to ditch. It just means that sometimes relationships and our needs change, and people who might be in our inner circle can be different from those that were there, maybe before the diagnosis, that can be threatening to a sense of self, because we may think that no people that I thought were close to me are not really my good supports, and I don't really know who my good supports are. So again, that that word curious is a good one to use is rather than imposing who should be in my life and who should be showing up for me, why don't we be curious and just look at who actually is a good support and who do I actually feel comfortable with? So those are kind of things that we may want to think about when we think about changes in our social roles as we navigate changes to our identity. I'm

**Speaker 2** 21:48

sure some of that change in relationships over time is still because of certain myths or in the community as to, you know, cancer? Is it contagious? You know, if that still floats around, even though there's absolutely no justification or no evidence that cancer is in any way, shape or form contagious. But people do sometimes separate themselves from that for that reason, but I think more commonly, it must be because of concern that this person's sick and then they may die and they don't know how to relate to them. And so the separation occurs as a consequence of that. Least that's my understanding of it. You probably have a more sophisticated understanding of it.

**Speaker 3** 22:30

I think everything that you mentioned there, Dr Evans is what can create a sense of awkwardness in social interactions. And so sometimes I patients tell me that they've always been a very social person, but after cancer, they find that they just want to stay close to home, or they don't really want to interact with others because they they're fearful of getting these awkward questions, or people who don't know what to say hey and so again, that can be a change to this sense of identity that the level to which we like to socialize may change, and that's actually okay, right? And it's not meant to be permanent, permanent. But also, I think sometimes there's a lot of misunderstanding about what a cancer journey is, and we can't control how other people may react to us,

**Speaker 2** 23:19

maybe just to kind of move towards the conclusion there's one other role, the vocational role, that you wanted to touch on briefly and and then maybe summate, what your thoughts are on, on overall, rebuilding your identity, how you'd kind of wrap it all together.

**Speaker 3** 23:39

Yeah, return to work. It's actually really nice that we're ending on this note, because usually when we talk about cancer survivorship, return to work is the last piece that we look at in terms of getting a person back to the way they were. I have to say, if someone's going through this right now thinking about return to work, you're not alone. You're feeling very anxious about that you're not alone if having a call with the insurance provider provides a lot of fear and discomfort because it leaves a lot of uncertainty about your own abilities to go back, but also questioning about whether this is work that you feel passionate about or are capable of doing, because all those things that we mentioned changes to cognition, changes to our physical ability, so we may not have the energy that we used to, changes to our appearance, how people relate to us. So all those things impact our ability or readiness to go back. And I would have to say that there are a number of really great programs to help with return to work. So one is, there is a return to work program offered through wellspring. And there, there are a lot of rehabilitation programs, like at can well exercise programs that, again, can help build that confidence. And I would also say that this is also a really nice area to get some counseling or support about therapy is not just about. Depression, anxiety. It's really about return to functioning as well. So this is something that is nice to bring up to your oncologist or your provider to discuss. So

**Speaker 2** 25:09

as we sort of wrap up this segment, and I think it's a terribly important segment, because it's not something we've talked about previously, and I don't think is talked about with patients very much. What would be your message to people who are kind of at the end of their their cancer treatment and then they're kind of going to try and transition back we rebuild their self identity? What, what would be your kind of final recommendations to it's all of the things we've talked about.

25:39

Yeah, just one message,

25:42

one unifying

**Speaker 3** 25:44

message, okay, no pressure, yes, be curious is a really good one. I just want to normalize, because I don't think we see a lot of messaging about this. Cancer does not end when chemotherapy or radiation ends. A lot of the healing and the recovery happens after treatment ends, and that can be a harder part, because there's no road map. It's not like six sessions of, you know, reflecting or being curious, then you're back to yourself. So during this time, it's really important to to think about what can be helpful for you. That includes, who are the people that can help you through this journey? It's always nicer to connect rather than do to do it alone, and what are the resources that might be available to you as you're rebuilding the sense of self. We all take pride in ourselves in different ways. So some of us may take pride in our physical ability. Some of us may take pride more in our cognitive ability, so focus on the area that matters the most to you, and start there first.

**Speaker 2** 26:46

Oh, that's very good advice. No, this is a topic that I think is going to become more and more relevant in the sense that cancer treatments become better and they are and people are getting back or have the potential for a longer life. It really is important that they address this, this kind of recovery. It's a kind of getting over the another aspect of the cancer experience. And it's really been quite illuminating to me to think through what and follow your thoughts on on how to do that in the various components that we consider as part of our identity. So really want to thank you for the work you're doing in this area and for this message, because I think it's so important to an increasing number of patients. So we've been talking to Dr Karen Zang at the jurors key hospital and Cancer Center, and it's just been great to have this conversation with you. Karen, thank

27:45

you so much. Dr Evans, thanks for having me My pleasure.

**Speaker 1** 27:51

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