Scott Redding:

Welcome to The 3 P's of Cancer podcast, where we'll discuss prevention, preparedness, and progress in cancer treatments and research. Brought to you by the University of Michigan Rogel Cancer Center. I'm Scott Redding.

We're here with Dr. Michelle Riba, Director of the Rogel Cancer Center's PsychOncology Program and Associate Director of the University of Michigan Depression Center, to discuss the use of warrior language for cancer patients. Her interests are in the assessment and evaluation of distress in cancer patients and their families, and was a member of the panel that developed the National Comprehensive Cancer Network's guidelines for assessing distress in cancer patients. She has spoken on and published on the topic of needing to change the way we talk about cancer to avoid using militaristic language. Welcome, Michelle.

Michelle Riba:

Thanks so much, Scott, I appreciate the opportunity to talk with you about this.

Scott Redding:

I wanted to talk to you about this topic because in the past year, both locally and nationally, we've lost or know of well-known people who have cancer. Aretha Franklin, Senator John McCain, locally, L. Brooks Patterson, and Jeopardy! host, Alex Trebek, who is undergoing treatment. The one thing that we hear about is that they lost the battle or they're battling cancer. Can you explain why this type of description might not be appropriate to use?

Michelle Riba:

It's important to understand that not everybody is the same, and people think about language in different kinds of ways. Generally, in terms of campaigns to raise money, opportunities to have people come out for different events. But it's also important to think about patients and families and how they interject or hear about these words, and what it means to them personally.

So the idea here is for us to have a conversation about the words that journalists use or people who we're trying to raise money, but also how that may be incorporated or heard for the individual patient and family. And sometimes, it's our understanding from the work that we're doing that those words can be problematic for patients and their families. It may make patients anxious, it may make them feel like they're failures, it may make them feel that they don't have control. And so it's important to have that conversation.

Scott Redding:

I'd like to go back to that point in a second, but as it relates to, say, journalists, when someone does pass away ... I can understand when we talk about it having that anxiousness for a current patient, but when someone has passed away, does it also affect the family how that's maybe represented, in that



Words have meaning (Completed 10/11/19) Transcript by <u>Rev.com</u> they've lost their battle, or maybe they didn't view it as a battle, but they did all that they could to be able to survive?

Michelle Riba:

Right. So in a lot of ways it's not them versus us, in some ways we also in the cancer world have stimulated some of this as well by using words like survivorship. When does survivorship start, and how do we understand that word? So for families, they are trying to figure out what their roles are in this journey. And so what does it mean for them when somebody else has lost their battle, what are they supposed to do in terms of armaments? And this metaphor, for a lot of people, doesn't work. It's sort of, in some ways, comparing it to some sort of a war or battle, and there is going to be a losing side and a winning side.

And it's really not about that. We try to help patients with all kinds of problems in terms of living a quality life, and trying to live with something or trying to live to their utmost best. And it's not so much the endgame, but how do we get through this? So we're trying to shift the conversation for all of us, patients, family, friends, and how to help people get the best care possible, and have the best life possible. Not so much winning or losing.

Sometimes surviving something is not enough, right? "I survived that test," or, "I survived going in for that interview." And so for me, when somebody talks about survivorship, that may not be what I really want out of something. So it's important to really ask people what's the goal, how can we help, and trying to develop a partnership with patients and families about this. And the words do have meaning.

Scott Redding:

We touched on the bad language, we touched on survivorship, and that we need to think about the words because words do have meanings. What if a patient or family member embraces that war-like metaphor language for what they're going through or their family?

Michelle Riba:

Well, we try to meet patients and families where they're at, and I have to say, I really don't have patients or families coming in using this language. So it's interesting, this dichotomy of seeing it as headlines and others using it, but the individual people who are coming in don't tend to use this language. So the idea is trying to help people with what their goals are and how they see themselves.

Often when people have significant health problems, one of the issues is that they don't see themselves the same way they used to see them, whether it's a physical change or often an internal, emotional change, and trying to help



Words have meaning (Completed 10/11/19) Transcript by <u>Rev.com</u> people ... They talk about the new normal, but really what is it that they want to get to and how we can help address that in different kinds of ways.

Scott Redding:

It's interesting, you said that a lot of the patients and their families aren't talking about that when they come in, about this language. But then there are campaigns like ... NHL has Hockey Fights Cancer. You've got the Ford Warriors, in the month of October, for breast cancer. ACS has different things periodically where they have fighting in that language. And yet you see people at these events, or part of that, that do kind of embrace that. Is it that they're embracing it because they want to be part of maybe a group? How do we get some of these organizations to think a little bit differently when it comes to those kinds of communications as they take on these campaigns?

Michelle Riba:

Well, one has to view a lot of these campaigns in a really positive way, that they're mobilizing large groups of hopefully wealthy people or donors to contribute to raising awareness, decreasing stigma, increasing research dollars that will go towards not only breast cancer, but we all have to remember that a lot of what we learn for one type of illness can be translated and used for other diseases. So it's important for all of us to sort of appreciate the work and the marketing and the communications that go into raising awareness and raising these funds.

I can tell you that some of my patients and families have voiced worries that so much is going into one type of cancer, what's going to be left for other cancers or orphan kinds of diseases? And so we have to do better communication about the idea that what we learned from one can be translated into another.

And to recognize that, in order to mount these types of campaigns, you may need to use certain kinds of motivators and language and publicity, that gets people to come out, and to walk, and to open their wallets and pocketbooks, that may not then be translatable into the individual person getting care. And so separating that and making those kinds of distinctions for people, I think, is something that we're interested in doing.

Scott Redding:

Yeah, when we talk about the language, and we talk about some of these larger campaigns, and the aspect of fighting and battles, does that in the long run affect a patient maybe in their potential outcome with either the treatment or what their final ending, so to speak, as we mentioned earlier, is with their disease?

Michelle Riba:

It's very hard to have cancer. It's hard physically, it's probably mostly hard emotionally, and a large percentage of people with cancer do have some sort of



ROGEL CANCER CENTER MICHIGAN MEDICINE

Words have meaning (Completed 10/11/19)

Transcript by Rev.com

Page 3 of 6

psychiatric condition during the course of their care. The figures are between 30-50% of people will have either depression, anxiety, adjustment, and other conditions through the course of care. So, if one combines the physical as well as the emotional, it's sometimes very difficult for people to think about fighting anything.

In fact, they're just trying to get through. They're trying to eat, they're trying to sleep, they're trying to get to their appointments. So for some people, the idea of being aggressive or taking something on is not actually where they are in terms of the space that they're trying to fill. And for families as well, just trying to get people to their appointments and make up for lost wages, or somebody who's not working anymore, or the change that goes on in families, is pretty powerful and difficult.

So the idea about being aggressive about this, and having that kind of control, is not really what we're trying to focus on in caring for patients. And so this is sort of, again, this dichotomy of what people are saying out there who may not be aware, or have never been through this, or maybe have had it but are not living in the moment, and the various difficulties that patients and families are trying to address.

So the idea is that we are trying to help people deal with these kinds of problems, and that's why we have these distress guidelines and we ask these kinds of physical and emotional questions all the time, and then try to harmonize for them what we're all trying to do in a partnership.

Scott Redding:

Most likely, because we know one in two people will have been diagnosed with cancer in their life, how do we give advice or let people know that sometimes using the words, "I had breast cancer too, and I beat it. You can do this as well," affect the person receiving that information? How do we help understand?

Michelle Riba:

It's very natural for us to want to align with the person we're talking with and offer comfort. And we do that in different ways, right? We can hug somebody, we can say, "I'm so sorry." But in order to make this a shared experience, sometimes we say things that may not be as helpful as possible. Some ways that we might do it is sharing what we've been through, and sort of saying, "If I could do it, you can do it." We may say, Anne Tilley or somebody else had something that may not even be the same illness, but we're trying to break bread, we're trying to figure out a way that we can be comforting.

And I have to say that people come in here and talk about some of this and how it's either helpful or not helpful. Some ways that work are to understand and



ROGEL CANCER CENTER MICHIGAN MEDICINE

Words have meaning (Completed 10/11/19) Transcript by <u>Rev.com</u> Page 4 of 6

appreciate that sometimes it really doesn't matter the stage or what the person has, because somebody may have an early stage and be very distraught compared to somebody else at a worst stage.

So it's important to listen and hear, and sort of bear witness to what somebody is saying. We all want to try to rush in and help, and the idea is to try to really just sit and listen first to what people are saying, and then ask, "How could I help?" Sometimes people don't know, and then ways to sometimes offer are to sort of say, "Well, these are some of the things I could offer."

And it may not be at that moment, you may think about it later. Bringing a meal, bringing somebody for an appointment, picking up children, bringing over books, magazines, sitting during an infusion appointment, making calls, purchasing supermarket goods, going to the post office, et cetera, et cetera. You can make up the list yourself. But just sort of rushing in and offering advice or aligning may not necessarily, for that person, be the right thing. And so the idea about hearing and offering, and not jumping to conclusions, may be the right way to go.

Scott Redding: And not everyone has the same makeup in how they want to deal with any kind

of medical diagnosis. Everyone has their own privacy, as well as what they want

to be open to.

Michelle Riba: That's exactly true, there's not one gold standard here for anybody. So

> appreciating that, and understanding that, and being respectful about that helps us all sort of think about this. And it could be for any illness, it's not just for

cancer.

Scott Redding: Well, Michelle, this has been really informative. If there's anything that I've not

asked that you want to make sure that people are aware of as it relates to, not necessarily militaristic language, but even just the aspect of words have meanings and words can play an important part in what people hear when

they're going through treatments.

Michelle Riba: It's important for patients and families to realize that they can become

> distressed sometime during the course of care, and that we have professionals who could help them. And whether it's words, whether it's their physical or emotional problems, we have a Patient and Family Advisory Council who's been

helping us with this particular aspect of this militaristic language issue.

At the end, it's important for us to realize that sometimes we can't predict, even though we think we can, but often we can't predict really who may be more



ROGEL CANCER CENTER MICHIGAN MEDICINE

Words have meaning (Completed 10/11/19)

Transcript by Rev.com

distressed than others. And so if that occurs, it's important to talk to your clinicians about that, and then hopefully we can get treatment quickly to people, the right treatment at the right time. So it's important that, when people feel that they're distressed, whether it's because of a physical or an emotional issue, that we as clinicians try to figure out how to get the best help possible.

Scott Redding:

Well, again, thank you for the time, I appreciate it.

Thank you for listening, and tell us what you think of this podcast by rating and reviewing us. If you have suggestions for additional topics, you can send them to cancercenter@med.umich.edu, or message us on Twitter @UMRogelCancer. You can continue to explore the three P's of cancer by visiting rogelcancercenter.org.

