

Speaker 1:

Welcome to the Cancer Aware Podcast, where we'll discuss cancer prevention, treatments, the latest in research and important news around cancer. Brought to you by the University of Michigan Health, Rogel Cancer Center. People with serious illnesses are often advised to consider palliative care and/or hospice, but what does that mean? Are they the same or different? And what does that mean for the other kinds of care that patients get? We are here today to hear from an expert in both, Maria Silveira is a palliative care specialist at Michigan Medicine and the Ann Arbor Veterans Affairs. She has over 20 years of experience working in the hospital and in clinic, taking care of patients with serious illness, supporting them and their families through what is often the toughest time of their lives. She helps train the next generation of palliative care and hospice physicians and nurse practitioners, and she does research in symptom management. Welcome, Maria.

Dr. Maria Silveira:

Thank you. Glad to be here.

Speaker 1:

So let's start with how we started this conversation at the beginning. What is the difference between palliative care and hospice?

Dr. Maria Silveira:

So primarily I would think of them as being different in terms of where they provide care. So palliative care is something that we offer in the hospital when patients are hospitalized or in the clinic when patients need that additional support because they're continuing to see their subspecialists, their primary care doctors, and they need another specialist that specializes in adding that additional layer of support. Hospice is a service that comes to your home, and it's usually at the point where you've decided that the main goal is to be able to stay at home, not go back and forth to the hospital, not go back and forth to the clinic. And what you are looking for is to be able to stay comfortable and have most robust set of services come to you.

Speaker 1:

You said that the palliative care happens more in a hospital, clinical setting while hospice is more at home. So with that being said, timing-wise, how long is someone getting palliative care when they are referred for that compared to when someone gets onto hospice care?

Dr. Maria Silveira:

So for palliative care, it really can vary and it varies primarily based on the preferences of the patient and their physician who is requesting that level of assistance. I've had patients in my practice for years, as cancer care has gotten increasingly successful, people living longer and longer, but with sometimes more burdensome illness. So I can be there essentially as long or as short as it is in the patient's best interest and their preference. Hospice, the way it's structured in the United States, the payment mechanisms for hospice require that you be able to state that you wouldn't be surprised if that person's end of life came within the next six months.

So typically folks are at a much more advanced stage and they've typically either exhausted treatment options, maximized treatment options, and are not getting benefit any longer, or have decided that

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those options are not acceptable to them any further, any longer. With that said, usually we think of hospice as something that's reserved for patients in the last six months of life, but again, there are exceptions. There are people who live for years sometimes on hospice, and so they get recertified and they can get recertified endlessly as long as their condition is still very severe. Palliative care, we have people, again, who come to us and we may only care for them for a matter of days or weeks. And then we have other people that, like I said, I'm with for years.

Speaker 1:

So why do people think they're the same?

Dr. Maria Silveira:

I think it has to do with the fact that historically our origins are the same. So hospice originated in the UK and it came to the United States primarily in the '70s, but grew in the '80s and '90s during the AIDS epidemic and then became an industry after Medicare officially set up payment mechanisms for it. And then palliative care was created as a way of bringing the same levels or types of support into the hospital and into clinics. Historically, we came from the same source, but as time has gone on, we've become increasingly specialized. So inpatient palliative care has actually grown tremendously to the point where all VA hospitals have palliative care, most large medical centers have palliative care as well.

It is available to most Americans when they go to a major medical center and hospice has grown as well. More people are dying with the support of hospice at home than ever before. But folks still confuse us to this day. Yeah, you could say that we both really make the patient's comfort and the family's well-being our core goal, but we are increasingly different. I think because of the fact that palliative care is growing tremendously on the academic side as well. There's increasingly more and more research and more sophistication and more science that's backing palliative care. Hospice, there's still tremendous amount of tradition, culture that drives the practice, although there's some science there as well.

Speaker 1:

Can you give us some examples of someone who is going to be having palliative care, what that might look like from treatments for them?

Dr. Maria Silveira:

So the typical person that I first am asked to see is someone who's having pain that their oncologist is struggling to manage with the appropriate medications, but they're usually at the point where the oncologist is not comfortable either because of they're not working any longer or the doses are high enough that the oncologist is feeling like it's outside their wheelhouse. And so oftentimes for me in the cancer center, I'm caring for people that are still benefiting from treatment, from aggressive cancer treatment. And oftentimes I'm also advocating for aggressive treatment because like I tell a lot of my patients with cancer, the best way to treat your pain is to treat the cancer. Everything I do, yes, can help, but it won't get rid of the pain. So by and large, probably about a half of my referrals are coming to me for pain management and a lot of other referrals come to me for other kinds of symptoms that people have, whether it's nausea, vomiting, that is again, not responding to the typical treatments the oncologists are recommending.

But then probably the remainder of folks that are having a tremendous amount of emotional distress or family distress related to their condition. And what I tell my patients is there's a lot more to having

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cancer than just getting treatment for the cancer itself. Cancer involves now rethinking, reimagining the kind of life that you're living, right? And in part to incorporate all the treatment you have to receive because the treatment itself is a job and managing all the visits to the physicians, the ongoing infusions, and then the side effects that you have, it really becomes a new life, new lifestyle. So there's a lot of adjustment that has to take place. Not to mention the fact that now you are carrying a diagnosis that by and large people still hear the word cancer and they imagine the worst thing possible that could happen to a person. And so there's a lot of sense of existential threat and a need to reimagine what the future will look like. And those things are very distressing to people and understandably so.

And I don't practice by myself for that reason, I practice with a team that includes a psychologist, social worker, as well as nurses, nurse case managers, and clinical pharmacists because the care of these patients can be so complex and no one person can actually do it alone. Not to mention it's emotionally difficult on us as well and so functioning as a team is really core to our ability to practice this for a career, to do this forever or as long as we can. But a lot of our time is spent helping people reimagine their situation in a way that doesn't feel quite as threatening and that they can understand and incorporate into their life plan in a way that feels less anxiety provoking. So one of the most hurtful ways to think through cancer is as a battle. And unfortunately our culture, our health system takes advantage of that as well, it's always, cancer is pitched as something that you fight.

But the problem is that when you can't defeat the cancer, you can't get rid of it entirely, the conclusion is that you're a failure or that you haven't fought hard enough or that you haven't gotten the right weaponry. So you apply all of these ways of thinking that come from the military world. But increasingly, cancer is not a battle that you win. It's a chronic illness that you live with. So when you look at the successes that we've had in places like prostate cancer and breast cancer, people are living for decades now with these cancers. They're not considered cured because you have to continue to get treatment for them, but you can live a very or close to very normal life despite still knowing that you carry this cancer, whether it's in microscopic levels, visible, invisible, whatever, it's with you, you have to cohabitate with it.

And so then it becomes less distressing when you have to have those interactions with the oncologist where you talk about the fact that levels are up and that you may have to change things if you realize that it's just like diabetes, we're just changing our medication, we're adding a new medicine, we're rotating to something else. When you view it more as how do we manage cancer as opposed to defeat it, all of those interactions that go on when the cancer is still there, but you're adjusting therapy, which are by and large, 90% of the interactions that happen, especially when people have a disease, a level of that they can't eradicate. Those interactions become far less threatening. They become more routine, how do we adjust things and keep going?

Speaker 1:

So I was wondering, you do research in symptom management and the way you describe treatment for palliative care seems like they would be synonymous and the same thing. So what do you think as far as talking about the confusion between palliative care and hospice of referring to, even though it's palliative care, of symptom management as a way to help with some of that confusion?

Dr. Maria Silveira:

We're all working on symptom management, the oncologist, the palliative doctor, the hospice doctor, what's in our arsenal can be similar, sometimes can be different. So I think it is just a question of at the very edges of your practice, who takes over? So for the oncologist, they have in their toolkit many of the

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same things that I have in my toolkit. The thing is that I have, a comfort level at a certain extreme that they don't have, whether it's managing opiates at very high doses or managing opiates in someone who's become addicted or had a history of addiction or managing opiates in people who have other conditions that make opiates more dangerous. The hospice physician or team, because it's primarily nurse practitioners that provide hospice at home, they have a level of comfort with how do you manage these things at home when you no longer have the technology that the oncologist and I have available?

So I have a lot of things that are available to me to take care of people's symptoms in the hospital that sometimes are not available if the goal is to be at home or how do we adjust those things so they can be available at home? So to some degree, we're all complementary. And so the question really becomes what's the patient's goal? What do they want life to look like at whatever point they're in? And then we bring in the different specialties to be able to provide them care where they're at, whether it's in the hospital, whether it's in the clinic and they're going home, whether they want to stay home, whether they're in a nursing home or a hospice or whatever. A lot of it is driven by where patients physically are, and a lot of that boils down to what patients want their lives to look like.

There's a certain point where that intensity of cancer care exhausts a person and their family, and it's natural for people to start to think, am I getting what I need out of this anymore? That coming in every three weeks for an infusion, dealing with side effects for a full week or two makes sense when you're able to bounce back and have a good quality of life in between. But when sometimes the treatments begin to take over and you feel like you're living in order to receive treatment or the treatment's making you feel sicker than the cancer, those are times where it makes complete sense for someone to wonder whether or not it's worth it anymore. And I think a lot of people get to that point, and those are the folks that I think we certainly take care of in palliative care people that are way earlier than that point.

But definitely when they get to that point where they're beginning to really second guess whether or not the treatments are of meaningful benefit to them anymore, we're definitely useful there. And hospice is definitely the best way to support people at home. It is the single most robust set of services that you could bring into a person's home when that is their goal. With that said, there are a lot of models that are developing. For example, at the VA, at the Veterans Affairs, we are able to give people hospice at home while they're still getting treatment from our oncologists. That is not possible still for the vast majority of adults who are on Medicare, but you could envision a future where our healthcare system changes so that you can actually get both still, you don't have to make the decision to give up anything. The decision to treatment would be divorced from the decision about whether or not to receive that level of robust care at home.

Speaker 1:

We spent a lot of time talking about palliative and hospice care as it related to cancer patients. Are there other people who have other disease that can benefit from palliative care?

Dr. Maria Silveira:

So we talk about people with serious illness, serious illness being something that really causes predictable decline. That's how I would define a serious illness, something where the treatments don't get you back to where you used to be and that what you need is really support for how you adapt, how you continue to purpose, joy in life and comfort despite having a physical decline. Those are all serious illnesses, and they could be things like congestive heart failure, COPD, emphysema in other words, dementia. But in a lot of these other conditions, subspecialists often can continue to have people feel relatively good, very good for very, very long periods of time. So you see palliative care used less often.

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For example, you've got pulmonologists, cardiologists, nephrologists that do wonderful work adjusting medications and can keep people feeling normal for very, very long periods of time.

And so for those conditions, unlike cancer where sometimes you initially know what prognosis a person has because of the type of cancer or the stage of the cancer and you know whether or not the chemo is curative versus palliative, as we would say, something that controls the cancer but doesn't cure it in some of these other conditions, you don't have that clarity from the very beginning. So even though palliative care is useful at the most advanced stages of those conditions, you don't see palliative care being offered early like you might in some cancers where the oncologist may know early on that the course is going to be difficult for that patient. So yeah, we have a role, but oftentimes it's difficult to figure out when that time is, and so often the indicator is when people keep coming in and out of the hospital for complications of those conditions where the specialists are trying to adjust what they can, but they're now at the very edges of improvement.

They're not getting those improvements that they did once. So we can be called in those situations and the same is true for hospice. Once hospitalizations, medications, IVs, things of that nature, further testing are no longer benefiting a person and the person has decided that they want to stay home, hospice can help. But again, it's often very difficult in those cases, the clarity is the issue. What's the future going to look like and what happens in a lot of those cases, for example, the congestive heart failure patients and the pulmonary patients with COPD, they've been hospitalized so many times in the course of a lifetime and felt so good. They've been rescued many times before and gone back to feeling well. It's hard to recognize for them when they may have gotten to that point where that bounce back is no longer there. So it's hard for their physicians to recognize it, and it's hard for them, themselves, to recognize that they're at a new place.

Speaker 1:

What current research is there around palliative care and/or hospice care?

Dr. Maria Silveira:

There is increasing research showing that when we are involved, patients can live longer. It depends on the condition, but for example, the study that got the most attention was a study where they did early palliative care for patients with stage four non-small cell lung cancer and involving a palliative care team at the same time as you started treatment with an oncologist, prolonged life expectancy by a month and a half, two months for someone who was expecting to have a pass from their cancer eventually. There's better quality of life, there's less distress, and there's a greater chance that you will have the end of your life, if and when that comes, at the place of your choosing. Hospice has also been shown to prolong life, so people who receive hospice and are able to have care that's focused on their comfort actually live longer than patients with similar levels of disease, certain kinds of conditions for example, certain cancers.

They can live longer with the assistance of hospice at home and presumably because what they would be doing at the hospital, you get to that point where you have diminishing returns. And I think that's what's really, again, getting to that point is hard to realize when the stuff that you did for the last bit of your life was so useful now has become burdensome and hurtful. That is very tough for both the patient and the physicians to recognize, whether it's that hospice itself does something to prolong their life or the fact that they're no longer getting treatments that come with the potential for life-threatening complications, hospitalizations that come with the potential for life-threatening complications, whether it's that prolongs their lives, avoiding those things that prolongs their lives or getting the care that

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hospice gives that prolongs their lives, I don't know. My suspicion is that it has to do with realizing when the treatments that were once helpful are now hurtful. I think that that's probably the thing that makes the greatest difference.

Speaker 1:

Well, Maria, I think this has been really great, really good information. If you were to have one key message around this topic, what would it be?

Dr. Maria Silveira:

I think the key message is for folks to realize that palliative care can be very useful regardless of where they are in their trajectory if they feel that all of their needs are not being met by their primary subspecialist or their primary care doctor. Particularly what I tell people is to think of us as the service that can fill in the cracks when things have gotten so complicated and you feel that your doctors are treating your disease but they're not treating you, palliative care can be helpful. Because essentially we are able to talk more with you about what are the implications of this physical condition that you have? How does it affect who you are as a person, how you live your life, and how you plan to live the life remaining, that's a space where we're very comfortable. The other thing I think that's important for people to understand, so we're a service on top of, and in addition to the other teams that you're getting, you're not giving anything up by coming to see us.

And our goals are really highly driven by what your goals are, the patient's goals. So we don't necessarily come in with an agenda to get everybody who comes into palliative care, it doesn't mean that we are referring everyone to hospice. Our goal is really to make sure that you're getting all of your needs met. Even those needs that seem like they're not medical, but they are definitely impacted by your physical condition. I always start my meetings with patients, that last bit is usually the first thing that I tell people so that they're not afraid. We're really here, you can use us as much or as little as you want, nothing's requiring that you be here. And so to the degree that you find us useful, use us. And if you feel that you're not getting a lot out of what we offer, you don't have to be here.

And so I think when people feel that it's really a choice, and also when we show them that we actually can reduce the level of distress that they and their families are experiencing, in part because we're open to having conversations that they've been afraid to have sometimes with other physicians because they don't feel like they're welcome. They don't want to give impressions that they're losing faith in their treatment or their doctor or their team when they realize it's a safe place to bring up all of those fears, people really do appreciate us, but it's not for everybody. Especially folks that are really dead set on never talking about how things might not work out the way you want them to, and there are those people that just have grown up with that mindset or culture where you can't discuss anything negative because it'll happen or they're too vulnerable, they feel when they do that. For those folks that might not be as useful.

Speaker 1:

Again, Maria, thank you for being here today and sharing this great information with us.

Dr. Maria Silveira:

Thank you. Glad to be here.

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