



Holistic and Supportive Care for People Living with Parkinson's
with Dr. Christopher Tarolli
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Davis Phinney Foundation

Melani Dizon (Director of Education, Davis Phinney Foundation):

Hello and welcome everybody to “Holistic and Supportive Care for Living Well with Parkinson's with Dr. Christopher Tarolli.” I'm super happy to be with you today. My name is Melani Dizon. I'm the Director of Education at the Davis Phinney Foundation, and this is a super important topic. And we're going to get down to all of the confusing language that happens sometimes and helping people understand when to use this, when to think about palliative care, where to go, who to see, all of those kinds of things.

Okay. Let's get started. Dr. Tarolli is a movement disorder specialist, neurological educator, and is the co-director of the Mind, Brain, Behavior neuroscience course at the University of Rochester School of Medicine and Dentistry. He's involved in clinical research that focuses on novel technologies, PA practice-based research and palliative care and individuals with Parkinson's and other movement disorders. All right. So first of all, let's talk about what palliative care is. We've talked often about how it kind of suffers for some language issues and how it kind of makes people worried. So talk us through—what is palliative care and who is it for?

Dr. Christopher Tarolli, MD (University of Rochester School of Medicine and Dentistry):

Yeah, absolutely. And just want to say thanks so much for having me today. Excited to be totally going through and providing some clarity for everybody on some of these topics. So I'll do my best to give as clear and concise of definitions as I can, though, I'll be honest, there are certainly some gray areas here, which is probably the reason that I think a lot of folks have some questions about this.

So we'll start with a very broad definition of what palliative care is. Palliative care is essentially symptom-directed care that is applied to reduce the burden of disease among patients with chronic diseases. Okay. So big things, again: reduce burden of disease, symptom-directed care, patients who have chronic disease. And the reality is, palliative care by that definition is actually really extremely broad.

Now, when most people hear the term palliative care, they think about a specific a specific form of palliative care or a specific type of palliative care called hospice care. And so I want to make sure I define that as well. Hospice care is also known as end-of-life care. And so, although the definitions of this vary based on the country that you're in, for most places in the United States included in this, that usually means, again, symptom-directed care that is focused on the last six, or maybe up to 12 months of life among patients who have a chronic disease.

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Just one other thing that I want to mention broadly about palliative care is that again, palliative care is a symptom-directed care, meaning that we are really having the goal of managing symptoms, reducing symptom burden, and optimally improving quality of life for patients. That does not mean that patients who are receiving palliative care cannot at the exact same time receive care that is either disease modifying or in diseases that have cures, you know, care that is curative. So cancer will be a big area where this would happen. Patients who have cancer will often be undergoing aggressive chemotherapy or radiation therapy or some other curative therapy, but can at the exact same time be involved with palliative care to really meaningfully address the symptoms to make sure that we're not only addressing the underlying disease, but also making sure we're keeping the person and their quality of life in mind.

Melani Dizon:

Great. So when we think about somebody with Parkinson's and if it's symptom driven, can you give me an example of somebody with Parkinson's that might have some sort of dominant symptom that is really beneficial for palliative care versus somebody who maybe it's not the best for, or it's not as necessary?

Dr. Christopher Tarolli:

Yeah. I will definitely answer that question. Before I do that, I want to talk, I think, a little bit because I think it's important for everybody to understand who is providing palliative. So you know, the way that I really think about this—in Parkinson's there are really three main groups of providers who are providing palliative care.

So as many of you probably know, unfortunately we don't have disease modifying or curative therapies in Parkinson's today, with the—maybe the exception of exercise being a potentially disease modifying—but we don't otherwise have substantial disease modifying or curative therapies. And so a lot of the care that your neurologist or your medical provider is providing actually probably *is* palliative care.

And when I say palliative care, I'm going to say to you that lowercase “p” palliative care, meaning that the symptoms, meaning that your neurologist is really helping you address the *symptoms* of your disease, trying to reduce those symptoms as much as they can. And so in that case, palliative care really has a role at all times, right? Every time you see your neurologist, you should be talking with them about your quality of life. You should be talking with them about the symptoms that are most bothersome or most burdensome for you. And by managing those symptoms, although we don't usually call it this, you know, again, in this broad definition of palliative care, that *is* truly palliative care. So the broad definition “palliative care” is really applicable at any time. But I think when most people ask this question, they're not really talking about that broader definition. They're thinking about more of what we call specialty palliative care, meaning their medical providers who actually have formal training in this care. And there is, in this case, actually two separate groups that can do this special palliative care.

Now, traditionally palliative care was a separate specialty, completely unto itself. Most palliative care providers were trained in internal medicine and did not usually have specific training in neurology. And so that has traditionally been where palliative care is. A lot of the focus on palliative care. This really came about in the sixties and seventies and has evolved over the past 40, 50 years now. But really the focus there early on was in cancer, but as time has gone on, we've recognized that palliative care is much more broadly applicable outside of the cancer world. And so that second group of providers, the medical palliative care providers, those traditional palliative care providers, they're really beneficial in the symptoms that patients should be thinking about potentially being engaged by a palliative care provider.

There are in symptoms like grief, pain, substantial psychosocial burden that comes along with the disease. Palliative medical, palliative care providers are particularly adept at that. And the other thing that medical palliative care providers are particularly adept at, though this can be done by any provider, really, is a concept called advanced care planning, where they actually talk with patients about what their goals are for their long-term care, talk about what they would want to be done in terms of interventions if they were no longer able to make decisions for themselves. And the goal again, it's called advanced care planning, is that that is done well in advance that those conversations are happening months or even better optimally years before you get to the point where any of that needs to be put into place.

Okay. So the first group, we said, your regular neurologists, are providing lowercase P palliative care. Medical palliative care providers are providing care that's more directed at pain and kind of global burden of disease, psychosocial burden of disease, and advanced care planning.

And then we actually now, over especially the past 10 years, have a hybrid group of specialists called neuro palliative care providers. Now, neuro palliative care providers are going to be the providers who are best equipped to provide palliative care to patients with Parkinson's, and formal neuro palliative care providers have training in both neurology—so they are neurologists, as well as in palliative care—they've done some special subspecialty training in palliative care, whether formal or informal. So this would be the group, for example, that I fall into, or I have some informal training in palliative care. I didn't do what's called a fellowship in it, but I've done training outside of that in palliative care in order to understand how to specifically do everything that a neurologist does, but also to do what the medical palliative care provider does.

And the reason that these providers are best equipped to provide care to patients with Parkinson's is because they have a good understanding of Parkinson's. As I mentioned, medical palliative care providers don't get a lot of education on Parkinson's and other neurological diseases. And so having providers who actually have that specific education, who can anticipate the symptoms of the disease, that are probably going to be most burdensome and who are able to not only address those symptoms but also able to do things like talking about advanced care planning, talking about grief, talking about goals of care, those things are what neuro palliative care providers can

do, and that the time of involvement for that, and actually the decision to involve those providers is, I think, dependent on a couple things, the first of which is unfortunately the availability of that. So, you know, we are fairly lucky here at the University of Rochester. We have a neuro palliative care center here. And so we have a number of providers, not just in Parkinson's, but in other neurological diseases, that take care of that, our neuro palliative care providers. And there are other providers around the country who do this, most of them located probably around or at a larger academic medical centers. And so I think availability is one major issue.

And then the other thing, and I can talk more about, you know, sort of when to engage those folks, if folks want to talk about that.

Melani Dizon:

Okay. Yeah. So let's definitely talk about the when, and also, you sort of gave us the big picture of the different types of palliative care, but if let's say I have been living with Parkinson's for a couple of years. I've accepted the diagnosis. I have a neurologist or a movement disorder specialist. But I moved to Rochester and I'm like, wow, there's this center. Who would I expect to see? And how often and what's the sort of protocol?

Dr. Christopher Tarolli:

That's a great question. So as Mel implied, neuro palliative care is not just a doctor. Palliative care, again, we're talking uppercase Palliative care—specialty palliative care whether it's neuro palliative or medical palliative care—this is a *team* of providers. So the palliative care provider, sometimes nurse practitioner or physician assistant, they sort of are at the lead of that team. They're meeting with you directly, but working with them is a whole group of supportive individuals. So there's often nurses that are highly involved to talk with folks about their symptoms, to actually specifically address that. Social work is very highly involved to provide psycho-social, to provide access to social supports. Many social workers are able to do some counseling, though, if not, there would usually be a psychologist or other counselor on the team who's able to provide that psychosocial support for people.

And then there are sometimes other people involved. Many palliative care groups will have a chaplain for people to explore more, not necessarily religious, but the spiritual side of disease and spiritual acceptance of disease. There is sometimes actually physical therapy involved to help with pain and discomfort involved.

And again, you know, the size of the team is going to differ based on where it is, but as Mel mentioned, it is really important to recognize that it's not just one person that you're seeing, but it's usually a team. In terms of what that visit or visits actually looks like, that's going to differ pretty widely. I think the kind of best palliative care models out there right now are having an actual, what we call multi-disciplinary clinic, where you would come in and not only be able to meet with the provider, but essentially be able to cycle through this group of providers for whoever will be useful for you.

So you are coming in to see a palliative care specialist. They identify what your symptoms are that are most substantial and say, “You know, what I think you would be, it would be great if you could meet with the chaplain and the nurse, and maybe the physical therapist today to talk about some strategies to manage those symptoms or those or those features of the disease that are really burdensome to you.” So I think that's the optimal way.

And I will actually say there've been a lot of things that have been in medical care that have been probably negatively impacted by COVID-19 over these past six months, actually interdisciplinary care has somewhat become easier because you can have people essentially in a Zoom meeting like this, and actually then just shift people between different Zoom rooms. And so I will say, you know, palliative care, this kind of multidisciplinary clinic idea in palliative care, has actually, you know, I think is thriving in this in this setting. It actually applies itself well here.

And then I know you asked a little bit about how often, and that's really going to be dependent on what the goals are of the palliative care. Some people come to palliative care with very specific symptom goals. They come in and say, you know, “My neurologist, I'm struggling with disease, you know, sort of coping with the understanding of,” or the grief that comes along with actually being diagnosed with the disease. You know, then you focus on that and you continue until that's been resolved. Some people have really severe symptoms that maybe their neurologist is less comfortable with managing—things like, you know, urinary symptoms things, you know, a lot of pain. And so again, the duration of care is going to depend on how well you're able to address that. So for now, most people, it's a consultative service, meaning you'll see them for a relatively short period of time, rather than following with that team for a longitudinal period.

Melani Dizon:

Okay. So when, is there ever a point where the person with Parkinson's would actually come in and meet, let's say, pre-COVID or post-COVID, with a lot of people at your center, like, Oh, well the neurologist, the chaplain, everyone's going to be there today, or is it sort of like a case management type?

Dr. Christopher Tarolli:

Yep. So at Rochester, our neuro palliative care center has just gotten off the ground, actually, in the past six months. So I can't say before that, but there are definitely centers out there. So UCLA, University of California, San Francisco, and then the University of Colorado, actually where the person who established our neuro neuro palliative care center came from, he was at Colorado before he came here. That was exactly what they had. They basically had a large room at the medical center and basically had stations throughout it. And patients would essentially, you know, kind of shift through the stations and actually meet with those folks. And that's the case in other specialty, you know, there are other multidisciplinary clinics that we do have, that that is exactly what we do also. We basically shift patients between different rooms and different providers, but they're all there located in one location on one day.

Melani Dizon:

Okay. Are there any of these services, let's say I'm like, I know Judy Long is a chaplain. We've done a lot of work with her. She's at UCF. Is there, or is it typical for a palliative care center to provide also services to family members or care partners of the person with Parkinson's?

Dr. Christopher Tarolli:

That is an excellent question. So I didn't mention this at all, but one of the really important things to know is that palliative care is, and I think we'll talk about this a little bit later, we say that palliative care is what we call "person centered care." So it really focuses on the person and their overall quality of life, recognizing that a person is not an island unto themselves, but they actually have a large group that is often around them. And so providing care and support to care partners is a huge part of palliative care.

And actually, sometimes actually very often, particularly in patients who are in more advanced disease stages, when I'm thinking about palliative care in those settings, that's really where I'm considering the support for the care partner, actually, probably being the most impactful thing that we can do. And so again, that support can include counseling—spiritual or psychological counseling—psychosocial, providing additional supports like providing home nursing services or connecting them with home nursing services in the home. And actually sometimes providing respite care where the care partner can actually take some time to themselves because we know that care partner burden is a huge, huge problem. And addressing that early and aggressively is really important to allow care partners to continue on in their role.

Melani Dizon:

Okay, great. Can you talk a little bit about the person-centered versus disease-centered type of care?

Dr. Christopher Tarolli:

Yes. So the easiest way for me to think about this or to explain it to people is thinking about what is the focus of the visit that you're going into. So in person-centered care, the questions that your provider is asking you and the visit itself are focused on your priorities, they're focused on what is the thing that is most impactful to you, and what can we do to manage that symptom or piece of the disease. In disease-centered care, the questions are very specific about specific symptoms. How is your tremor, how is your OFF time? And the focus of the treatment is on managing, is on the provider really managing those symptoms specifically. And often what is the focus of the visit ends up being on what the provider prioritizes rather than what the patient prioritizes. And unfortunately I think what we see is that a lot of care, for a number of reasons, ends up being disease centered.

And because of that, it is probably not adequately addressing the priorities of patients. So one of

the most important things that I tell my patients to do, and I encourage every patient to do, is to go into your visit with your list of priorities. Because as many of you know, Parkinson's, number one, is not just a motor disease, right? It's not just tremor and stiffness and slowness and changes in your walking. There are lots of other things, right? Constipation, autonomic problems like drops in blood pressure, you know, mood changes. All of those things are a part of the disease. And I think everyone will recognize it's not feasible for a provider to go through a list of each of those at your visit. And because of that, a provider will kind of default to the things that they feel most confident in managing, which usually is motor symptoms, which often is not the symptom that is most impactful for patients. So I tell all of my patients, I would encourage everybody on this webinar today, go into your visit with your priority. Say, these are the top one, two, maybe three things that I want to talk about today, because that way you can at least push the visit toward patient-centered care and not have it end up focusing on something that's maybe not as impactful or not as useful for you.

Melani Dizon:

I think that's a great point because we have a lot of people that are from very different places in the country. Some are very rural or suburban and inner city. And they may not have anything like a place that provides integrative care, palliative care, supportive care, anything like that. And so the goal is for you to be the advocate and to turn it into a supportive-care visit. So turn it into that. And you can, by making sure that you come in prepared.

One of the questions that I get, and I have gotten a lot is, "Okay, this is fabulous, but there's nobody in my area that does this. They don't think like that. I am in and out. It's, you know, I'm just another cattle going through. There's five minutes and I get my doctor," and that kind of thing. So what is it that somebody can do, aside from having that mindset that "I want this type of care to piece it all together," without it feeling like, "Oh my gosh, I'd have another job, to get this kind of team together." What can they do?

Speaker 2 (24:13):

That's a great question. So I think everything you said being an advocate for your care, or if you're a care partner being an advocate for your loved one's care is the number one first step that you should be doing. Number two. And I think as part of that, again, I don't want to be putting work more work on people, but you're all doing this already. So I don't think I'm saying too much to this group, educate yourself, know what the symptoms are that can be part of Parkinson's and that can be addressed. You don't need to know what to do to address them, but no, you know, I think many people don't realize that things like depression or anxiety are not just a part of, or not just, you know, come along aside, Parkinson's, they're actually a part of the disease. And most providers should most neurologists and movement disorder providers should hopefully be reasonably comfortable at least with initial management of some of those symptoms.

Dr. Christopher Tarolli:

I think that's going to be the case for many of the non-motor symptoms. I think it is a challenge for folks who really feel like even if they do all of that, they're still not getting what they want from their provider. I think in that case, you know, I think you have a couple options. If you can find other community support, see what is available in your community, talk to other support groups in your community, if you have them, to identify if there are folks that other people in your community have found to be very beneficial. I will also say again, I don't mean to harp on kind of COVID right now, but for anyone who's comfortable with telemedicine, for at least probably the next few months, I think we will have some ability to provide care a little bit more broadly.

Now, for most states, it is still going to be state-specific, but that at least broadens the area that you could go to and broadens the number of providers that you could potentially see, where you could potentially see somebody who maybe does have a little bit more comfort with palliative care without having the additional burden of having to drive one, two, three—you know, I know some places out west, people are driving two, three, four hours sometimes to get to the next biggest city — where somebody might be telemedicine offers at least some benefit for that. And so I think that's another potential option that you can look for.

And then again, continuing your education with things like this, so that you know what to be looking out for yourself and what to be thinking about in terms of next steps.

Melani Dizon:

Great. So for those of you watching that are interested in, and you don't have this at your fingertips, one of the things that you could do is kind of become your own palliative care case manager, and maybe your care partner can help you. And you say, "Okay, if I'm really going to look at my entire well-being, I'm going to look at, I need somebody to help me with my motor symptoms. I need somebody and that's going to maybe be my movement disorder specialist, or my neurologist, or my primary care, if that's all that's available to me. A neuropsychiatrist or a psychologist who's going to help you with some cognitive issues or some, maybe depression and anxiety. Maybe a physical therapist, maybe a social worker to help with some of the counseling issues and stuff with your family. A chaplain, if that feels like a fit to you." And kind of go down the list and say, "These are all it. You know, in a perfect world, if I could have all these people on my team, this is what I need to feel good."

And then you can kind of work to figure out, how can I schedule all this? And even more importantly, which I think is so great for the center that you have, is people, your people are communicating with each other. And so that's one of the big values of having something like that. And if you don't have it, you know, if you find and create the contact person, that can then be the person that kind of shares the information and keeps everybody on track. You can create your own center where you are because most people are going to be able to find, even if it's separate physical therapist from their speech, language pathologists over there.

Dr. Christopher Tarolli:

I think, I just want to say, I think that's a great point. You know, I think again, if you go back to what I said and exactly what Mel said, if you have to prioritize, what is most important to you and your disease? You can identify where a provider, you know, even if you don't have one of these more integrated teams, you can identify what type of provider might be most helpful for you to address and to manage some of those symptoms. And just like Mel said, to create that team for yourself locally, where you are. So, yes, I think that's a great point.

Melani Dizon:

Yeah. And also, if you, let's say you have a doctor who is disease centered, that no matter what you do, you go in and you're like, "Well, wait a second. This is a really big concern." And they're like, "Well, you know what, this is what we're going to deal with. You know, we got the tremor, we're going to fix that." You can find another doctor. You're not always stuck. You always have the power to go look for somebody else. And I think that's where support groups, especially local support groups, can be so fabulous because you can say, "Hey, this is a concern I'm having. Does anybody have any ideas?" So you always have some control. And if it does mean you have to drive a little, it usually—everybody that we've talked to that said I had to switch doctors and I ended up having to drive a couple hours or even go to a different state—it was worth it because they help them with the care that they need.

So a lot of times what we talk about and what comes up often, and we definitely talk to Dr. Tarolli about this a lot, is this idea of a Parkinson's roadmap. So what can people expect in general when they think about how Parkinson's kind of progresses from the day that I get the diagnosis to later, let's say there's no palliative care center where they just go, and then people can do an assessment and figure out what they need. What can they do on their own to think about, okay, here, let's say I'm 60, I've just been diagnosed and I'm looking out ahead. What does a roadmap look like?

Dr. Christopher Tarolli:

Yeah. So this is a good question. So we'll talk kind of generally about overall trajectory. But also I think just given the focus of the talk specifically, think about where those peaks of burden are, right? Where are those peaks of potential need for something like palliative care, where might it be needed?

So the first place actually, and there's some advocacy out there now, and some push to do this, the first place is at the time of diagnosis. So there's some really, you know, excellent literature out there communicating with patients, you know, there's this classic paper that we talk about called "Dropping the Bomb," right? That idea that the diagnosis can feel like such an incredible blow to somebody. That is actually probably one of the periods of highest disease burden in the entire disease.

And it's often not the time when the symptoms are most most burdensome. It's because people don't know what to expect. They often feel lost. And so that diagnosis is actually often one of the highest points of need for palliative care. And there's now some push to try to standardize some more palliative care in those early disease stages.

Now, in terms of disease trajectory and disease progression, you know, there are definitely differences among people. We have always kind of said, everyone's Parkinson's is different. But that being said, we can certainly talk about averages and talk about kind of what a general roadmap looks like.

And for most people that involves some slow progression of disease, usually over a period of somewhere around seven to ten years. And then after that seven-to-ten-year time point, usually with more substantial burden coming, I will say beyond that point of diagnosis, usually in those first, you know, five, seven, ten years, the need for palliative care and sort of more you know, substantial goal-directed care is generally a little bit lower.

Obviously there are exceptions to that. There are people who have really substantial non-motor symptoms early in their disease course that need to be addressed. But again, on average, that, that early portion of the disease, the burden is generally fairly low.

It is when you get to that seven-to-ten-plus-year period where some of these needs become a little bit more substantial. So, you know, I think the loss of independence that comes with the disease, that's often a very challenging time for folks. Where their balance is more challenging or they're needing more assistance around the house, the loss of the ability to drive. Again, kind of that loss of independence. Something that I think everyone is concerned about—another place where kind of the burden of palliative care from a psychosocial level might be burden of the disease, sorry, from a psychosocial level, is very high and where palliative care might be beneficial, and again, as the disease burden continues on, with the disease, you know, beyond that ten-year time point, that's, I think, where especially if your provider is not super comfortable, that's where you might be thinking about integrating some other folks into your care to sort of manage some of those symptoms that maybe your neurologist is not as comfortable with.

Melani Dizon:

Great. So somebody asked, "What if I can't get in to see my movement disorder specialist more often than every six months? Who else should I make sure that I'm seeing between my visits with my MDs?" And I know some people are even, you know, longer than that. So who's a good person to see.

Dr. Christopher Tarolli:

Yeah. So I think it depends on what your needs are, what your symptoms are, what are the things that you want to be addressing? That's going to direct this. I mean, frankly, I think a primary care

doctor is actually often able to triage fairly well many of the symptoms that you have. Now, I also know there are some primary care doctors who will say, "Well, you have a neurologist. Why don't you talk with them about that?" And we'll sort of differ, but I think if you're really having trouble with your neurologist or movement sort of specialist office, your primary care doctor is certainly the place to start.

And then again, I come back to this idea of creating that team where you are identify what those symptoms are that are most impactful to you. What can you be doing to address those symptoms? And think about who other than a movement disorder specialist might be available to address them. If they are Parkinson's specific symptoms, that really should primarily be addressed by the movement disorder specialist.

Again, I think, you know, educating yourself and reaching out to community as best you can. I don't ever purely advocate for people kind of doing something that is just being said in a support group, but your support group is a great place to at least have a jumping-off point for where you should start. The folks there can help you think about how to manage; many people will have struggled with the same symptom or same problem and can give you ways that they've maybe coped with it or ways that they've managed that. And so I think that's a great way to build that community around you, to feel like you have some support if you don't feel like you're getting it from your provider.

Melani Dizon:

Right. So what if I'm not religious? What's the value of having a chaplain on my team?

Dr. Christopher Tarolli:

Yeah, that's a great one. So I think most people think of a chaplain as being specifically religious. So what a chaplain though is educated to do, they are educated in all religions, first of all, but I, you know, our chaplain that we work with really refers to what she does is more spiritual care or spiritual guidance. So that's basically, I don't want to mischaracterize what she says or what she does, but you know, what she basically does is she focuses on your sense of your place in the world, your place more broadly, and that might have a religious anchor to it, or it might have a completely secular non-religious anchor to it. And so what she can help you do is just, you know, she really helps you kind of zoom out and see how everything kind of fits together. And actually our chaplain often functions in the counselor role with that sort of broader focus on sort of where you are in the world or, you know, more broadly, in the universe. Right. So just kind of that focus on zooming out. And again, it may have a religious focus, but if that is not what your belief system is, it can definitely have a completely non-religious focus.

Melani Dizon:

Yeah. And so one way to also look at it as like a social worker. Sometimes we have licensed clinical social workers. There are also medical social workers, and they might be, you know,

they're more apt to work in a hospital on a team like this, but a social worker could be somebody that's going to provide you counseling, if they're a licensed clinical social worker, and where your chaplain, they might not be super religious, but they might be more educated around mindfulness techniques, around some techniques that are meditation, mindfulness, and breathing and things that are a licensed clinical social worker isn't necessarily trained to do. So they're kind of taking from many different disciplines. So you can kind of look at it like that. And also if the chaplain turns out to not be a great fit for you, and even if there's not a social worker on that team, you can go find somebody else to do that with.

Great. What was I going to ask you? Came to me and I lost it. Does anybody have any questions? Or tell me this? Yeah, actually, that's a great question. Why did you decide to get into this work? And you said that you have, you know, you didn't do a fellowship in palliative care, but you did some extra training. What made you want to do that?

Dr. Christopher Tarolli:

Yeah, so I did my training in neurology and recognized that I wanted to be in a specialty where I could continue to follow patients for the long term. And movement disorders and Parkinson's specifically really seemed like a the place where I felt like I could make the most impact. So what I recognized was in Parkinson's we do a reasonable job, I think, of addressing motor symptoms and keeping those under fairly decent control. I think most movement specialists can do that. What I recognized was there was a huge other group of symptoms that were just being neglected and not adequately addressed. And that's really where and why I wanted to focus on this area. So I actually really focus on, again, they're called these non-motor symptoms. Again, things like mood symptoms, anxiety, constipation, urinary, you know, memory and cognitive changes.

These are often the things that are more impactful for my patients and the things that unfortunately have traditionally been really under explored by providers. And also we just don't have a great way to systematically assess those. And so that was the major reason why I wanted to get into this. You know, before I went to medical school, I volunteered with a hospice program, and my entire framing of medical school and residency was actually done with that lens of optimizing quality of life over quantity of life. And that's really exactly what palliative care does, and that's why I wanted to get into this work.

Melani Dizon:

Great. Let me see, Oh, somebody asked about payments. Is a center like this, where they go and they get all of this stuff, is this typically covered? And how does that work? I mean, I don't want to get a nitty gritty of healthcare insurance, but is this something that's typically covered for people?

Dr. Christopher Tarolli:

Yeah. So for most people seeing a palliative care specialist is going to be just like seeing any other sub-specialists. So if you see a neurologist or cardiologist or anything like that, palliative

care falls into that group. They're a specialist basically. So yes, almost everybody's insurance will cover this.

The multidisciplinary care is different. Often those centers are actually supported by grants because the center is not actually reimbursed for those additional services, but again, that's not typically costs that's passed onto the patient. Usually it would still just look like a subspecialty visit.

Melani Dizon:

Okay, great. So I'm going to ask, who can offer the best care for a patient with Lewy body dementia in addition to Parkinson's?

Dr. Christopher Tarolli:

Yeah, so again, I think a movement disorder specialist is the place to start. But that being said, I think geriatricians probably have some experience. And then geriatric psychiatrists to treat patients more broadly with dementia are also theoretically specialized in that disorder. I will say, you know, this is probably my personal bias as a neurologist, I find that they tend to focus and have a little bit more of their expertise in Alzheimer's disease. And so that's why I think a movement disorder specialist is probably a little bit of a better option, but that frankly probably differs between centers. So like that's maybe the case at the University of Rochester, but somewhere else, the psychiatry group is maybe a little bit more of a person to do that.

I still think, though, a palliative care provider is certainly applicable to patients with dementia, with Lewy bodies. And so I think they could certainly supplement the care, again, if there are specific symptoms or specific parts of the disease that the primary provider is not feeling totally comfortable with.

Melani Dizon:

Great. Another question. "As a caregiver for my husband, constipation management is a huge problem for both of us. The usual treatment suggestions result in explosions, not regularity. Is this just part of my husband's MSA advancement or more treatable than that?"

Dr. Christopher Tarolli:

Yeah. So I'll definitely comment on that. I'm going to zoom out actually a little bit, just given the last question and this one. So you know, most people are familiar with what with Parkinson's—or what we call idiopathic Parkinson's or run of the mill Parkinson's—there's this group of cousins of Parkinson's that we call the atypical Parkinsonian syndromes. Dementia with Lewy bodies; multi-system atrophy (or MSA) being among that group. And what we know, and again, just given that the focus of today's talk is on palliative care, what we know is that the burden of symptoms and burden of disease is much higher in those groups, and our ability to treat those diseases is unfortunately generally lower or less effective than in idiopathic Parkinson's. And so in these diseases, actually even more of a push to involve someone like a palliative care specialist who

really can help to focus on, again, these kinds of non-motor symptoms and this overall quality of life, because the burden of those diseases tends to be a little bit higher.

In terms of the management of the constipation, you know, I think this is going to be quite variable depending on the person. There're a lot of different strategies we can use to manage constipation or to get bowel movement regularity under control. And so I would encourage you to continue to work with your provider. Sometimes you know, medications are a little bit more activating and can result in sort of jumping from, you know, constipation to diarrhea or really overactive bowel movements. And so I would encourage you to continue to work with your provider to see if you can just maybe find an alternative strategy that's maybe not quite as activating but still gives that symptomatic benefit.

Melani Dizon:

Great. What about, so someone asks about alternative care, like acupuncture massage, and I think more general, those are great. Is this something that these kinds of providers are in a palliative care clinic?

Dr. Christopher Tarolli:

So I would say probably not, probably not going to be integrated into the palliative care clinic. That being said, I know, and I talk to my patients about things like acupuncture and massage therapy. We don't, you know, we don't have great evidence out there because nobody's done a good study of these. That doesn't mean that they're not effective. And again, these interventions are generally so low risk that I often very strongly advocate provide patients considering and trying them because if they get benefit from those, that's great, that means that we have something that's not a medication that's offering you symptomatic benefit.

So not something that's formally integrated into palliative care or into my practice but definitely something I discuss. And so alternative therapies are certainly things that can be discussed. And again, it's always that balance of the risk of the alternative therapy versus the potential for benefit. It's always what I consider again with, you know, acupuncture and massage. That potential risk is extremely low and the potential for benefit is reasonably high. So that's a great like ratio that I would say yes, absolutely. You should try that.

Melani Dizon:

Great. And thanks everybody for asking your questions. It's really helpful. Somebody asks how likely or common are substantial cognitive symptoms in Parkinson's? And actually maybe within that question, talk a little bit about the Lewy body, the Parkinson's dementia, kind of unpack a little bit of those to get people on what this one is.

Dr. Christopher Tarolli:

Absolutely. So I will say, cognitive symptoms, memory symptoms are very common in Parkinson's, in a run-of-the-mill idiopathic Parkinson's. We estimate that by about ten years into the disease,

probably somewhere around 60 to 80% of patients will have some memory or cognitive symptoms, and that can progress to full-blown dementia, which basically just means a decline from your prior function that causes a difficulty or challenge in day-to-day life. By 15 years, that's clearly closer to 80% with a more substantial cognitive symptoms. Something like dementia. So very common, but much later in the disease course in idiopathic or run-of-the-mill Parkinson's disease.

This is in contrast to dementia with Lewy bodies, where the cognitive symptoms, the memory symptoms, come early in the condition. So by definition, patients have to have the onset of cognitive symptoms within a year of the onset of their motor symptoms. So within the year of onset of tremor, stiffness, slowness. Now the reality is—I will be honest with all of you—this is probably a false differentiation, a false dichotomy. These are probably one disease that exists on a spectrum. One has cognitive symptoms really early; one has cognitive symptoms really late. And we treat them very similarly. But again, for right now, we do still differentiate them or say that they're two separate diseases, but we were generally thinking about management fairly similarly between them.

Melani Dizon:

That brings up an interesting point. So there was recently an article about “Parkinson's is two different diseases, one of the brain, one of the gut.” And then I talked to Professor Bas Bloem, and he said, “Actually, Parkinson's is like a hundred diseases.” So that's sort of speaking to what you're talking about. It, they all live in that world. That are probably brain and gut related and the timing of everything is different. But what are you doing differently if it's starting earlier versus later?

Dr. Christopher Tarolli:

Right. There's not a huge, huge difference. And what you said, there's a hundred diseases, right? That's the idea. Again, we always, there's still, I think, this idea out there that Parkinson's is motor symptoms, right? And that's due to the problem with dopamine and that part of the brain that needs dopamine to allow you to move. It's called the basal ganglia. But the reality is Parkinson's develops the gut. Parkinson's involves other parts of the brain. And it's that involvement elsewhere in the nervous system that produces these other symptoms.

And so again, this is really why we need to be systematically identifying and addressing these symptoms as best we can. And as I said before, specifically on the cognitive side, you know, my interventions are fairly similar. I'm going to use the same group of medications for dementia, with Lewy bodies, as I would for Parkinson's. And I'm still going to be asking patients, what are the symptoms that are most bothersome for you? You know, for many it's the cognitive, some others they have, they can have some trouble maintaining their blood pressure. So I'll aggressively manage that. Some patients with dementia with Lewy bodies, their motor symptoms are actually

just as burdensome, and we'll use medications like Sinemet or carbidopa/levodopa. And so again, our management strategy is fairly similar. It really is just depending on what the goals of our therapy is at that point.

Melani Dizon:

Great. So someone asked about Zoom out of state. So I know that Dr. Tarolli is in Rochester and he, did you know, we actually funded a study around telemedicine and there's a big push. I guess the question is now, I think that some, obviously some laws have been a little—they've moved. They moved really quickly because they had to with COVID. What is the case now in terms of getting care outside of the state with another doctor and is that happening now, but it might, you know, restrict again and go back to the state or what's the status?

Dr. Christopher Tarolli:

Yep. So this is going to differ based on the state, but well, let's actually start pre-COVID. So pre-March of this year. Doctors have had to be licensed in a state to provide care there. Now, most doctors weren't doing telemedicine because there weren't great reimbursement models for telemedicine at that point. That wasn't a problem, right? Patients could come. So for me, I see patients who come from Pennsylvania, from Northern Pennsylvania, they drive a couple hours up to see me here in Rochester. That's not a problem because I'm seeing them in New York state. So I'm providing my care in New York state. Where the problem comes in is now that telemedicine is expanded and will likely remain expanded—though, again, we need to see what the laws look like in the next six, 12, 18 months—is that you can theoretically provide care anywhere.

Unfortunately, most of those state licensure laws are still in place. There was a wave of many of those for a few months, but mostly in September, which was about six months into the waving of those licensure requirements were put back into place. So I know I have a lot of patients who will spend their winters in Florida. I unfortunately cannot see them in Florida nowadays, and that's based on the licensure requirements in Florida. So again, it's going to depend on the state. But I would say it's probably more challenging now, but I would anticipate that that is probably going to be brought in or become less strict as time goes on, especially if telemedicine remains a relative standard of care. And I, you know, I really hope and think that it probably will.

Melani Dizon:

Great. Okay. Any other questions? Someone's asking about COVID. You know, Parkinson's makes COVID more dangerous to the patient? I think anytime, right, you have something that's like you're, you're ill in some other way. COVID can be more, more dangerous. You're just more compromised. And that's probably, I would guess, depending upon how far you are in Parkinson's and what your main symptoms are, that'd be right.

Dr. Christopher Tarolli:

Yeah. I think that's right. I think the concern about potential complications is maybe where that comes. It looks like, you know, there's nothing that clearly suggests that patients with Parkinson's

are more likely to get the virus, to get COVID than anyone else, but keep in mind COVID is more dangerous already in older populations. Most people with Parkinson's are in that, you know, young-older adults to older-older adult population. And so they naturally fall into that higher risk population anyway. So I, you know, I've been pretty strongly encouraging my patients to take precautions as best they can.

Melani Dizon:

Okay. Great. Last question. Is there a connection between Parkinson's and hormonal imbalance? Do you know of anything? Someone's asking about people who work with that specialty?

Dr. Christopher Tarolli:

Yeah. So I don't know specifically about, I guess I'm not entirely sure what they're referring to with hormone balance. So we'll just talk about a couple things. I think a lot of people, when they say hormone imbalance, they often mean that they'r, there's kind of two things that I think about it. So the first is is challenges with sexual function definitely associated with Parkinson's. There can certainly be sexual dysfunction and among patients with Parkinson's, that can be something that we can certainly address. The other thing that I often find is that patients often have either heat or cold intolerance. They really have a lot of difficulty managing that. And again, very similarly, they could be part of Parkinson's as well. I hope that answered your question. It does depend a little bit on the symptom itself. You know, sexual dysfunction, certainly a urologist for either men or women is a reasonable option. And for some of the cold or heat intolerance, you know, maybe sometimes an endocrinologist might be useful in that setting, a general endocrinologist or managing kind of hormone levels.

Melani Dizon:

Great. All right. Well, we blew through that hour. Thank you so much for being here with us today, everybody. I'm going to put my email in there. So if you have any questions that come up about this topic, feel free to email me or any topic, actually, just feel free to feel free to email me. We'll be sure to send you the recording of the webinar and the audio, the transcript, and everything else. And thank you, Dr. Tarolli, for being here.

Dr. Christopher Tarolli:

Thank you so much. It was really great to be here. Hopefully this answered some questions for folks. Have a great day, everybody. Thanks.



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