



Demoralization, Meaning, and Parkinson's

A Conversation with Greg Pontone, Indu Subramanian, and Bradley McDaniels

Davis Phinney Foundation

Note: This is not a flawless, word-for-word transcript, but it's close.

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

Hello, my name is Melani Dizon. I'm the Director of Education and Content at the Davis Phinney Foundation, and I'm really excited to be here today to talk to several doctors on the topic of demoralization and apathy, and meaning in Parkinson's. And right now, I'm just going to have them go around the room and introduce themselves, tell us who they are and how they got into this work, especially with people with Parkinson's. Dr. Pontone, can you lead us off?

Greg Pontone, MD (Director of Parkinson's Neuropsychiatry Clinic, Johns Hopkins Medicine):

Sure. Hi, I'm Greg Pontone. I'm the director of the Parkinson's Neuropsychiatry Clinic at Johns Hopkins. And the focus of my work has been to learn to better diagnose and treat neuropsychiatric symptoms and Parkinson's disease.

Melani Dizon:

Great. Awesome. Dr. Subramanian, how are you?

Indu Subramanian, MD (Neurologist and Director of the Southwest PADRECC (Parkinson's Disease Research, Education, and Clinical Centers), Neurologist at UCLA Health):

I'm good. How are you doing? Good. So, my name is Indu Subramanian. I am a neurologist here in Los Angeles. I run our Parkinson's Center of Excellence at the VA, which is one of six centers in the country that take care of veterans with Parkinson's. And I also work at UCLA. I have a background in yoga, mindfulness, and integrative medicine and I've been most recently interested in the effects of social isolation and loneliness in Parkinson's patients.

Melani Dizon:

All right, great. And Dr. Bradley McDaniels.

Bradley McDaniels, Ph.D., CRC (Assistant Professor, University of North Texas, Department of Rehabilitation and Health Sciences):

Hi, I'm Brad McDaniels and I'm at the University of North Texas. I am the coordinator of our rehabilitation studies program here. And got into Parkinson's. My mom was diagnosed about 10

years ago at this point and led me back to graduate school late in life. A complete change in the trajectory of what I thought I was going to be doing at this point. But nonetheless, am excited to be here and have gotten connected with, your other panelists here talking about these things, apathy, loneliness, meaning all of these things that really make a difference in how someone does.

Melani Dizon:

Right. Great. So, let's start there. How did this trio come together and what are some of the things that you've been working on? Brad, if you can start us off.

Bradley McDaniels:

Yeah. You know, it, it kind of just happened serendipitously. I got to be friends with Heather Kennedy some time ago. and through her connections, I ended up talking with Indu and she and I chatted for a little while and we found out we both have some common interests in these areas. And she and I started doing some writing together and had a couple of projects re late earlier this year. And she said, you know, we need to bring Greg in because she's had him on her show. And I've seen those interviews and I thought, yeah, we would be a great fit. And we've just had a lot of fun, you know, all of us together. I think that we come into this saying, how can we make someone's life better with Parkinson's disease at the end of the day, that's, we're not trying to say we're going to cure apathy or we're going to take care of depression completely because we know we can't do that. But if we can just make one person's life better tomorrow than it was today, I think we've been successful in what we do. and it's really, to me it's about having people who have a shared commitment to doing that. And it's nice, I'll be honest, working with people when we don't have egos in the way because those things can be troublesome, right? We just, we just all get along and I think that's, that's the common thread that has kept this partnership and relationship going.

Melani Dizon:

That's great. So, I would love to hear you know, clinician side Greg and Indu the goal is to make people with Parkinson's better, right? To make their lives better. When you are seeing patients in the clinic, Greg, what are the, what is, what do you see as like some of the primary things you can do to help them?

Greg Pontone:

Yeah, you know, so as a psychiatrist, I think for me, what over the 20 years that I've been working with Parkinson's that stands out is I've been very fortunate to work with some really great neurologists who can treat the motor symptoms of Parkinson's disease very well. And I started to notice that there were people with Parkinson's disease who had the same level of motor impairment and yet having different experiences in terms of their quality of life. And we

started to think about what explains this difference. And there was a study from the Parkinson's Foundation that showed that depression could have nearly twice the impact as the motor symptoms. And so, we started to look at more of these emotional and mental symptoms that came with the disease. And noticed that when we treated them, not only did their quality of life go up and, you know, their mental health improved but that their physical ability to function improved.

And so, I think to me that was the biggest you know, sort of recognition points of recognition that we could do a lot more by really approaching the individual in a more holistic way. Not just focusing on one set of symptoms, but really looking at the context within which they live. You know, what are their struggles and their needs, and what's their mental health like? And so, I think that's been the most gratifying thing, is knowing that we can really have a big effect, on their day-to-day wellbeing.

Melani Dizon:

That's great. And Indu, you have a unique approach in terms of bringing in the Western and eastern medicines together in your practice. Can you talk a little bit about what you're seeing and how you have been able to help people live better?

Indu Subramanian:

Yes. I mean, I think as Greg was saying, you know, historically we've taken care of a relatively new population probably of sort of older Caucasian men well, who are, have wives that bring them to their appointments and have, you know, a certain sort of setup. And we've taken care of motor symptoms historically pretty well. I think we do that pretty well. But then, you know, what about all the people that aren't those people? And also, you know, I think when you do talk to people living with Parkinson's and there, their loved ones you know, what really matters to the patient is often something very different than a tremor or something that we can, you know, kind of measure in the clinic. And we've been sort of as clinicians almost trained to be laser-focused on the motor symptoms. And if we've helped, you know, gate speed, then you know, we're great, we're doing awesome, and go home.

But, you know, people can be really suffering with tremendous non-motor issues, and the mental health issues I think can be tremendously impactful and patient after patient, you know, when you survey them, say this, and really, when you start talking to people and listening to people really that's what, you know when you ask them, you know, what is, how are you doing? You know what bothers you the most? You know, why are you not able to do the things that you love to do? It's really these non-motor mental health issues. So, I just have always been a little bit more open-minded to thinking about the person in front of me, understanding them for who they are. I think that's why I was drawn to neurology because I love the stories. I love, you know, understanding, you know, what makes somebody tick and helping them to, you know, keep doing that.

That's just who I am as a person. And so, once you start to learn about those things and really meeting people where they are listening and hearing, I think you end up really sort of engaging the patient in a different way and they feel like, hey, tell me what I can do. You know, I don't want just a pill. I don't want just a surgery. I want to be part of, you know, this sort of solution. We've also have so many inspiring patients that have done really well. And, you know, we're trying to understand, we call it the secret sauce, you know, what is it that that patient that you meet that you know Greg had described, you see the same amount of motor disability, or they look kind of on paper the same one person's just doing amazing things and thriving and the other person is, you know, the opposite of that. So, we want to kind of encapsulate some of these things to you know, help people do better. And I think that's where, you know, the mental health kind of concepts and in that holistic approach and sort of the value of a psychologist and a psychiatrist who spend hours, you know, getting to know our patients and have been trained in a very different way, I think it is really helpful.

Melani Dizon:

Yeah. Great. So, let's dive into one of the topics that you are all investigating and looking at. Certainly not talked about a lot. I don't know if anyone else is talking about it. So, Brad, can you tell us about what is demoralization and then what impact is it having on people's life with Parkinson's?

Bradley McDaniels:

Yeah, yeah. You know, it's interesting. There have been just a few studies written about Parkinson's disease and demoralization and, but it's not really been delved into, you know, mostly what's been written has said, what is the percentage of patients with Parkinson's disease who have demoralization? And that's great to know. But there's so much more. And I think that, you know, this really got started some work Greg and Indu and I were doing, and Greg brought this up and he, he's like, what about this concept of demoralization? And we see it in the cancer literature all throughout the cancer literature. As people are getting close to dying palliative care, you begin to see this demoralization set in. And the challenge is a clear definition, right? We've had to be able to define a problem before we could do anything about it.

And we're getting there, I think, with demoralization. And then the second question is measuring it. How do we, and what instrument do we use? So, I think from a definitional standpoint, a guy named Jerome Frank was probably the first, I think, to really bring this up back in the sixties. And he describes it as an inability to cope. That's what it begins with. You've got this problem that shows up in life, this stressor, and it exceeds your coping capabilities. And as a result, you end up feeling hopeless, helpless me, you lose meaning in your life. And a subjective incompetence. And when I say that I don't mean that someone is truly incompetent in how they live their life, it's the incompetence of how do I deal with this new challenge in my

life, right? You get this diagnosis of PD, and you go, I don't have any idea what I'm going to do with this.

I don't know anything about Parkinson's disease. I don't know what the next step is. and so, I think it's challenging and all of those things combined I think result in a decrease in self-esteem, right? How do I feel about me? I've lost something that's really valuable to me. And I think that one of the, and the second part of your question, Mel, was about what that means to people with PD and right. I think some of the sequelae from that we see are going to be very similar to what you see with depression, right? And I'll, I'll probably defer to Greg and let him talk about that in a second, about how do we tease those things apart. But, you know, I think that someone who comes in and is experiencing demoralization is probably going to express loneliness.

I suspect they're not going to be actively evolved in the Parkinson's disease community. They're probably going to have some signs of apathy. It may not be a clinical apathy that we see. It might be behavioral apathy. But nonetheless, they're having apathetic behavior, probably having some anxiety in their life, right? All of these things that we commonly see if people with PD. And so, they're, and that I think is kind of this challenge. You've got this coalescence of all of these different diseases, or we'll call it a syndrome. Demoralization really is a syndrome. Because it's not in the DSM five. So, we don't really have a mental health diagnosis associated with that. But I think it's fascinating. and I think that when Greg brought that up and I began looking into this line of questioning, I thought, wow, this fits completely with people with Parkinson's disease. I've watched it with my mom, you know, when you get to see someone on a regular basis and I get to see those things that she's dealing with, and you kind of just begin to lose hope. Yeah. It's like, I know, this is going to progress. It's not going to get better. There's not going to be any type of a cure as far as we're concerned in the near future. So, it's tough.

Greg Pontone:

Yeah. And it sounds like there's, there's sort of two pieces to this demoralization part. It's this, however, we want to define it as the ability or inability to cope. Yep. But the big piece there is the lack of self-efficacy around it. I don't know how to do it and I can't do it and I'm not going to be able to do it. Right. So that just leads to like so many other things which Greg had loved to talk about. We talked about depression. How do you, how do you parse these things out? What, what can somebody look for? And in particular, as much as we want everyone to go to a neuro-psych and go see a psychologist and that kind of stuff, a lot of times it's the care partner looking at looking inside and they can observe. What are some things that you notice?

Yeah, so this is, you know, you can have both, you can have both depression and demoralization, and demoralization can trigger depression. But I think fundamentally depression is more of a biologically caused brain disorder. And whereas demoralization is more of an amalgamation of sort of cultural biases and beliefs and societal pressures and disease stress and everything sort of colluding together to undermine the sort of self-efficacy and

willpower of the individual. And I guess that's a good and bad thing because of demoralization there are many ways to sort of intervene that are helpful. You know, you can intervene by giving the caregiver things that can help the patient cope or you can rearrange the social network to provide more support. Whereas depression as I mentioned, it has a biological element and will most often need some sort of medication therapy for a full recovery.

And the other thing that sort of differentiates demoralization from depression is because you can be sad in both cases, and you can have low self-esteem in both cases. You can feel guilty about things you haven't done or haven't done as well as you'd like. But with depression, you're going to have changes in your sleep-wake cycle. You're going to have changes in appetite and sometimes weight. You're going to have trouble concentrating and being indecisive. So, you know, things that clearly indicate a change in what we call neuro-vegetative status. And I think when you see those additional symptoms, you start to suspect, and a clinician will diagnose that there's more than just demoralization present and then usually initiate the appropriate therapy for the depressive disturbance.

Melani Dizon:

Okay. So, Indu what is your experience of that with patients, but then also how does it tie into loneliness?

Indu Subramanian:

Yes. I mean, I think it's quite complex. So, there are definitely patients that I meet upon diagnosis that have been having non-motor issues of Parkinson's for a while and mental health issues for a while. and there are definitely studies that show that patients with Parkinson's can present with depression and anxiety at diagnosis. And you sort of see them, many of them are quite anxious, quite depressed, and you have a sense that, you know, unless I get this person sorted with those symptoms you know, they're not going to thrive and be able to deal with their motor issues or anything else about, you know, moving forward with the types of things that we ask them to do just to function in life. And so, you know, so often, you know, it's not terribly common, but I will sometimes start an antidepressant or send a patient on to a psychiatrist from the get-go.

And you definitely get a sense of that. Then there's the people who I think, you know, come in, we give them the diagnosis, or they've heard the diagnosis from somebody else, we're sort of confirming it and they send, they tend to get into this sort of a sort of funk. It's sort of this icky kind of feeling of an amalgamation of, I guess, you know, what we talked about, a lack of coping, lack of feeling in control, a lack of, you know, sort of motivation to be able to move forward in some positive way. In some ways, you know, when we all were dealing with, you know, and stuck at home and we didn't know the world was like, you know, imploding and healthcare providers were dying, and we didn't have enough PPE. There was this sort of, I think an amalgamation of some of similar sort of feelings.

It was like, you know, I want to have control, I want to be able to help, I want to be able to do something, but I just have this inability. And it's almost sometimes paralyzing, you know, to sort of, and I don't know what we would have to ask Greg and Brad if it's similar, but I know like I just had these sort of, you know, just a horrible sort of feeling of just, you know, whatever it was sort of mix of things and really a difficulty coping. So, I think when we, we see people like that and we really are trying to give them skills to move forward, you know, in a positive way. Many people when they feel they get the diagnosis, and there's definitely some people who, you know, feel somehow to blame in some way, or that they're, you know, ashamed or that they're guilty or that, you know, all of a sudden now if it's a young woman, you know, and she's a mom, you know, I, how's this going to affect my ability to take care of my kids or, you know, my husband or, you know, the other sorts of roles that I play in life, you tend to then sort of isolate because you feel alone and you sort of get into these sort of spaces of you know, getting more and more kind of feeling like there's nobody that's going to understand you, that there's something, you know, really, you know, that's very uniquely wrong with you.

And often people don't necessarily tell others about the diagnosis. They sort of retreat and they kind of have to start to kind of go through almost, I think some stages akin to grief, you know, verse denial and then, you know, eventually kind of getting into this more of an acceptance phase. But, you know, in those phases when people are really needing help and they need support, they often find ways to not get those. And it can make things a lot worse. And sometimes we see people, you know, five, 10 years later after getting a diagnosis. And I think how it's, how the diagnosis is delivered sometimes may also impact them that finally are seeing the light of kind of why, you know, having people in your life can make a difference or there, you know, finally present back to you to get help because they really do get derailed for a period of time.

And I think if we can just help people to realize from diagnosis how common this you know, is this sort of reaction sometimes to the diagnosis, the coexisting mental health issues that can be tremendously disabling and get proper treatment. And then the importance of, you know, support, like, you know, getting other people that have the disease may be to talk to or, you know, being able to include your family or, you know, if you're a woman, you know, may not be your husband, but it might be your best friend or your sister and, you know, bring that person to your appointment and start to talk to them about, you know, how you're feeling. And just that sort of not feeling alone, just feeling connected, feeling supported, I think can be part of the medicine for sure.

Bradley McDaniels:

Yeah. Hey, Mel, if I may, I just want to tag onto what Indu just said. One of the things I think that's critically important that she shared was helping patients to normalize this process, right? It's not abnormal to have a reaction like this when you're diagnosed with a chronic incurable illness. Right? And so, I don't see, see patients, but I can imagine them coming in thinking,

what's wrong with me? Right? and the truth is there's nothing wrong with you. This is a common reaction, and you know, we've talked about it in some other stuff. We've done reactive depression that happens, boom, you get this, and all of a sudden I can only imagine for me that everything in my life would just come to a halt. And now I'm mean.

Melani Dizon:

The odd thing would have no reaction to it.

Bradley McDaniels:

Yeah. Right. Yeah. And that's the thing is I think so many patients just need to feel normalized, right? For the way that they feel and the struggles that they're going through. And once we can normalize that, then they kind of can relax and come back down to some, someplace where we can begin to have these discussions about. Now let's delve into it a little bit.

Melani Dizon:

So, right, so, you're in a unique position, your mother has Parkinson's, and you've sort of been there along the journey. Can you talk a little bit about what happened at the beginning and anything, anything that you've seen in her progression that has to do with things like demoralization or anything?

Bradley McDaniels:

Yeah, you know, my mom is very fortunate. She is very grounded in her faith. And so, spirituality is a huge component of her disease process. and you see that in all the literature too, right? When you look at meaning in life and all of that, spirituality is a strong component in that. And I think that there's a direct correlation between those who do well and those who have some type of spirituality, whatever that may be. It doesn't have to be a singular religious belief, but something in a power greater than you that you focus on. So that has, has kept her largely level. She's gone through some depression. I don't think that she had as much of the reactive depression or the initial demoralization. Partly because, you know, she's, she was in her, she was 66 when she was diagnosed which is a lot different, right, then some of these folks whom I know who E O P D are, right, who are diagnosed in their thirties. That's a much different response.

But for her, I think that she handled it well. She's had ups and downs, she's struggling, mainly, I think what she has the biggest issue with is her cognitive abilities. Her motor symptoms are managed greatly. And that's, that's what Greg was just talking about, the movement disorder folks know how to manage that stuff. You give somebody the right amount of cinema and they're probably going to be okay, but it's these other things. And, you know, I talk to her and

it's not unusual every day I talk to her, and it's not unusual that I hear the same thing three days in a row. And you know, I don't have the heart to say, yeah, mom, you told me that.

But that's her struggle is she says, Brad, I just don't remember. Like, I used to, you know, I feel bad that we go to someone's house to eat and next day I see them at church or wherever. And they ask me, how did you enjoy it? And she's like, I don't even remember being there. and that's hard. But I think she's got a wonderful support partner. And my dad who's still alive, who's still very active, she's got a community around her. And I mean, she's got all of the things that we all talk about are essential for someone with PD. The one thing that she lacks that she struggles with is the exercise component. And but you know, I can only push so hard on her, right? I mean, I think, I was talking to my wife, and we said, you know, my mom's struggling to exercise.

And she's like, but how many people do we know who don't have Parkinson's, who don't go to the gym? Right? So why should we all of a sudden expect someone that they mean that they're diagnosed, they're going to spend five days a week in the gym? Right? But I, I've been fortunate seeing her and I haven't seen a lot of the ups and downs that I've seen with other patients whom I've come in contact with and who I talk to on a regular basis. But I think to me, that soul component with her is the spirituality component that she understands this is just how life is and this is what I was dealt, and I can either choose to go with it or I could give up and she chooses to go the positive route and say, how can I use this disease to maybe be an example for someone else who's diagnosed early on and can look at me as someone to follow.

Melani Dizon:

Right? So, I want to get into that meaning in life. Yeah. But I'm also curious, Greg, Brad just brought it up a little bit about the difference between, you know, early onset, later onset in terms of these types of issues that we're talking about today. Are you, is there a discernible notice between those two groups of people?

Greg Pontone:

I think absolutely. And I want to touch on something that Brad said before I address that more directly because I think he said something really important. I just want to bring it back to emphasize it a bit. He mentioned that for his mother, you know, faith was important, and it sounds like it was the moving force for acceptance. You know, she chose to accept the disease and move forward. And I do think before you can move forward on some level, you have to accept it. And sometimes that's facilitated by faith or science or your social connections or your care partner or your family or good physicians with whom you have rapport. But I think that's a really important aspect of this is that you can't really deal with something, and this is true across all of medicine and behavioral science until he accepts it.

And so, I think this is a crucial thing that I'm, I'm glad Brad brought up and his vignette about his mother, because I think regardless of how you find it, you need to find it. Okay. and then I guess this will hopefully segue into your question about does age matter in terms of age of onset. And I can tell you that when I started my career, that was one of the most shocking things to see is it almost appeared like two different populations. You had this group that when I read the textbook, this is when Parkinson's is supposed to happen right? In the mid-sixties, and, you know, you sort of, it's easier to accept, right? Because it fits into the mold. And then we had this other group that were, you know, kind of mid-career like me with young children who all of a sudden are diagnosed with this disease.

And I really think that the challenges, you know, you could say the fundamental disease symptoms are similar. There might be a difference in terms of you know, milder progression and early onset, but fundamentally the symptoms are the same. But the challenges in life are different. You know this group is trying to raise a family, and continue their career, it's a whole different set of worries. And you know, I think when you're diagnosed with this, all the assumptions you've made about the trajectory of your life, about what, when I'm going to retire, if I'm going to have a vacation home, like all, you know, all the things, you know, am I going to go to Europe when I retire? Should I do it now? All these assumptions that you've made, you have to realign your assumptive world to accommodate this huge thing, right? This huge thing that you feel at, at the beginning. You have very limited or no control over it. And so, I think that's really one of the problems that you have because there's, I just think there's a lot more lot more going on and many more variables early in life that you have to accommodate when you introduce the disease. That's not to say that it's easy at the more typical age of onset, but certainly, I can tell you that that's a challenge for many folks with younger onset disease.

Melani Dizon:

Yeah, I think one of the things that I definitely notice just from working with all of, you know, our community is that some of the people who are diagnosed older have already had to in some ways struggle with that meaning and purpose in life because they retired or they had already stopped, and they went through, like, they went through that, not to say they don't go through it again, but they had to learn how to find new meaning that their identity is no longer what their job was, or people knew them for a certain thing. And then people who are younger diagnosed have to give up work. There, you know, forced to give up early. And that feels like a really big piece of that ability to find meaning in life when that thing you may have worked your whole life to do gets taken away from you. You don't have,

Greg Pontone:

No, I think that's a great idea. I mean if you think about our identities, right? How do you define yourself? The majority of us define ourselves by one of the three things you just mentioned, our occupation, profession, right? You know, I'm a doctor, I'm a teacher, I'm a lawyer or their social roles, I'm a mother, I'm a daughter, you know, I'm a spa I'm a husband, I'm a wife, whatever.

And when you have the disease, all of those things, your competency is at least hypothetically challenged,

Melani Dizon:

Right? So, Indu, when you are seeing people with Parkinson's, what aspects of the meaning of life in the, in the meaning of their life come up and what are some of the things that you notice when they're struggling with that?

Indu Subramanian:

I mean, I think a lot of this is not something that we've ever really pinpointed, right? Our visits are so short, we really focus on, you know, a patient coming in with a complaint. You know, I have this problem, I fell down and, you know, I have a balance issue, right? And so, we, we bill for a complaint that comes in and you know, we're like, this is, you know, your piece of the world right now, you can call, complain to me about one major thing. I write it down, I bill for it, and then I do something about it. I send you to physical therapy or I prescribe a pill. This is like very reactionary, right? We sort of like really thinking about just, you know, compartmentalizing care in visits with complaints. So, I mean, do many of us sit around and talk about meaning in life?

And have we even thought about this in our own selves? I think that this is not something in medical school or anywhere that I really sat down and really thought like, you know, know these transitions where if somebody loses their identity, you know, they were doing this you know, profession, and now they aren't. And like, so how are they going to move forward every day with looking forward to the day and sort of creating an infrastructure to really, you know, thrive for the rest of their lives? I've seen this in a lot of physicians actually that retire and they kind of come in and they're like, you know, I used to be the one sitting in your chair and telling patients what to do, and now I'm here and you are telling me what to do. And it's a very different, you know, sort of sense of, you know, the roles that people play.

And so, I think, you know, just being open to understanding these dialogues, you know, so, you know, it's like what brings, what brings you joy? What brings you meaning, you know, starting with a conversation like that? How are you doing? How are you trying to incorporate that every day in your life? And how can we, you know, maybe make some modifications to really think about, you know, ways to help you to sort of get those things that are important to all of us? I think that dialogue is not being had by probably most neurologists and maybe some of the psychiatrists and psychologists, but, you know, often even they are reacting to something as a limited resource once something is gone wrong. And we're sort of like rapidly trying to help somebody in a psychotic situation or a major depressive episode or something like that.

So, so I think, I think creating a framework where we normalize these conversations and understand that, you know, for me this matters as you are a doctor and you know, for,

obviously for you as a patient, it should matter. How can I help you to find things in your life that create meaning? And, you know, many people are, have these things, they just have no idea that this is something that they should be, you know, spending a little bit more time on. So as Brad mentioned, you know, we talked about, for example, spirituality, you know, and we talk about, you know, even in the loneliness conversation sort of this societal connection with some group in your community that shares your meaning sense of meaning or purpose. You know, it could be a religious organization for many of our communities, and people don't realize that that is, you know, part of the medicine that sort of strong connection with people that care about you, that you look forward to going to see on Sunday.

Can I incorporate more of that? If you love church, if you love singing, if you love these people, maybe, you know, enhance that. So, I think it's about sort of stopping you know, the sort of classic way of entering you know, medical care, which is reactionary and looking for a symptom and really sort of spending a little bit of extra time talking to people about really what brings them joy and meaning, and then trying to enhance those things and really listening to, you know, some, sometimes, you know, it's very simple strategies. You know, I really love, you know, going into nature, I love going to the beach. Well, then let's try to get you to do that more. You know? So, I think, you know, as doctors or whoever, finding more ways to kind of cultivate this and recognize these things that are important to patients you know, and can be very meaningful you know, I think is part of, you know, know what we should be remembering to do in these sort of interactions.

And Brad and I wrote a paper on meaning life and, you know, there's a table that we added about, you know, things that can be impactful. And I'll, I'll let him actually speak to those, but, you know, it's sort of like they're worth some things. We don't like to do research or write papers when there's not a, so what can we do about it kind of angle, because, you know, it's not, it shouldn't be just creating stories about doom and gloom and then like, okay, so then what, you know, but yeah, I'll let Brad speak a little bit about the sort of things that we had talked about you know, that are, that are actually quite doable, I think, strategies.

Melani Dizon:

Yeah, that's great. And also, Brad, I, because we had mentioned that there is actually some research on there in the cancer community about this interested to know, like what you learned from looking at that research, and then as Indu said, what are some of the things that you now are able to kind of put in front of people with Parkinson's to help them?

Bradley McDaniels:

Yeah, so one, I just want to circle back to one thing that Greg said that I think is important to catch is he talked about the assumptive world, right? And it's important to understand what that means, and that's thinking how do we as people think our lives are supposed to look, right? And we, we have this path that we're set on. We have our careers, we have our friends,

and we have our kids. This is where I'm going to be when I retire, when that gets derailed, meaning and purpose goes down, right? Because now all of a sudden I've got to reevaluate everything and, you know, my significance if I lose my job like Greg said, my significance was in being a provider for my family and making money and being a respected worker at the job that I work, whatever that is. And all of a sudden now that stuff's gone, and you go, what in the world am I supposed to do?

And who am I? Which I, it's funny because Greg was talking about that I ask my students all the time in my classes, I say, A great question to ask a client is, who are you? Because who are you is very different from what roles do you play, right? Who are you is something that's in here, right? What I do is different. And so that's a whole other conversation, but it's an interesting topic to really think about who am I at the core? And that doesn't have to change, you know, my identity on the inside. But as far as what I learned from, the demoralization literature in particular was how common it is, right? Depending on where you look, I saw evidence of 14 to 50% of people with a variety of chronic illnesses report with are coming with demoralization. Now, the one study that was done in patients with Parkinson's, I think back in 2018, showed about 18%.

Which I would, Indu and I were chatting, I would argue that it's probably higher than that. It was a small, I think they only had 94 patients in that arm of the trial. So very small, but nonetheless in the world of cancer, clearly there are issues with that. Meaning in life was talked about a lot in that literature, because frequently, right? You're getting to the place where it's palliative care, end of life is coming for a lot of these cancer diagnoses, and you're beginning to question those things. What is my life all about? What happens when I die? and so I think meaning has become one of the therapies for dealing with demoralization, right? You can, you've got C B T that you can always use counseling theories. You've got things that, you know, Indu kind of talked about that from a clinician's standpoint that, you know, adequate symptom relief and good communication and adequate listening to your patients, right?

These things that will all help. Because lack of information is one of the things that lead, that can lead to demoralization. You just don't understand. And if I understand what to expect, which in Parkinson's can be really difficult because what patient A is going to get is not the same as what patient B does. So, it's really hard, right? When they say, what can I expect in the next five years? And you go well, it's not going to get better, right? I mean, that's probably the one thing I can tell you is going to, how it's going to go. But I think the meaning in life component really stood out to me as I looked at what was written about demoralization and how common it was and really that you, it's funny because you just don't run unless you're one of us here who's looking for this kind of stuff, you probably haven't even heard about demoralization.

I mean, if you're not a researcher and you're not reading the literature, you know what the word demoralized means, probably from Webster's, but you don't really understand what

impact that has on someone with a chronic illness unless you're digging in. And I think that as I began to look at the literature it became very clear that this is something that I think is extremely common in the Parkinson's population. I don't, I'm not going to put a number on it, but I would strongly bet that it's more than 18% of people, I'd probably argue more towards the 50% mark, maybe even more. I don't know. But it's a lot. And I think that it's certainly something that I'm excited about. and the three of us are really interesting, interested to begin to look at what does this mean for the PD community, and can we find those nuggets that we can say, because what Indu said is always the thing I, you know, when anytime I write something, my mind says, so what? Right? I can put a correlation between X and Y, but if you can't change X, then it really doesn't matter, right? So how can we move the pendulum forward is kind of a challenge.

Melani Dizon:

Yeah. This really reminds me of the idea of on and off and how for such a long time, part of the issue has not been how many people have off, and what are there, there was, it was the language around it. They might come in and just say, I'm in a bad mood, right? Like, they're talking about it differently. And so, in terms of like, how many people are experiencing demoralization? What, are they calling it? They're, they're not calling it that word, right? They're experiencing it and feeling it in really different ways. And so, the more we're able to talk about that word and then give different words, talk to the people, talk to the Parkinson's community, and say, what do you, how do you, when you describe this, what are you saying and what are you saying to your doctor? And what can your doctor take away from this? Right?

Bradley McDaniels:

That's super important because the issue is there, the language might not be so, because I bet, Mel, I bet that most of them would say I'm depressed, right? Because the symptoms are, are very similar. Greg talked about those. And I think really for me, as I look at how those two words differ, I think the incompetence is kind of the piece that fits with the demoralization that I just don't know what to do. That's not necessarily depression, that's just a manifestation of not understanding the disease process. And, but I bet you that they're saying depressed. And then the challenge for those of us who want to investigate this is being able to tease those two apart. The same thing we see with depression and apathy, right? a lot of those, yeah.

Melani Dizon:

The care partner might say he's just so apathetic. Yeah. And they're not getting right to like, what's, what's maybe that demoralization piece and saying, hey, there's something you can do, right?

Bradley McDaniels:

Yeah, exactly. Yeah. It's fascinating stuff. And I think there's so much there's so much out there that we can bring to the forefront and just begin having these conversations because that's when, to me, that's when the answers come. You know, when the three of us get on a call and we just chat, that's when ideas just start to flow. When you say, have you thought about, have you thought about? And I think that as we, like you said, Mel, as we get patients to begin to articulate more specifically what's going on with them, it allows people like Greg and Indu to better treat what's going on because they need to hear the patient say, this is what I'm dealing with, you know, just saying, I don't feel good. That that's really tough for a clinician, a doctor to deal with, what, what don't, what's not feeling good? Can you tell me specifically? And then when they can verbalize that to Greg and Indu, then they can go, all right, now here, we, I know which way to go. Do I need a pill? Or do we need some type of behavioral intervention instead?

Melani Dizon:

Right. So, I guess, Greg, what would you say from all of this work that you guys have been doing and writing and researching and thinking about this topic, what are some things that may have changed in your own practice based on this information?

Greg Pontone:

Yeah, so, you know, one of the things I think that's really become clearer, you know, sometimes the better you can operationalize something, the more precisely and more effectively you can intervene. And so, you know, we're talking about these constructs that are different, but overlapping, you know, depression and demoralization. And, you know, at the end of the day regardless of whether you have depression, demoralization, or little or both, we were thinking, what types of things can we do that will be successful and helpful regardless, right? And so, what it comes down to, and this is, you know, Brad really sorts of tuned into an eye onto this is something called self-efficacy. So, this idea that regardless of your disease or state, that you have the ability to impact the trajectory of your life. And so having this belief that you can change outcomes is fundamental to quality of life and you know global health, frankly.

And so, when you look at self-efficacy, it's probably more predictive of global health outcomes and quality of life than the severity of your Parkinson's disease, or whether you were diagnosed early or late, almost any other predictor that's used in the disease. Just knowing if the person has a robust self-efficacy is a better predictor. And so, if that's the case, we really need to develop interventions, you know, social behavioral interventions, cognitive interventions that restore or improve self-efficacy. And, you know, sometimes it's more than one thing, right? So, if you have a person who's depressed, you're going to need to treat that depression. But then in tandem, you do things that sort of restore that sense, of their ability to alter their outcomes. So, some of that, as Brad mentioned, is education. You know, just letting them know what's normal and where, where the sticking points are and how to overcome them, how to enlist the appropriate aid. And so, I think that if you were to say, boil it down to one thing that's really come from Indu secret sauce in this investigation is that, you know, they're restoring the



patient's agency is probably the thing that's been overlooked. In terms of our approach. We're good, we're good at treating the motor symptoms if you get 'em to the appropriate mental healthcare workers. We're good at treating depression, but we're really, we just don't have a protocol that's well developed for, for these other things like self-efficacy and restoring agency.

Melani Dizon:

Great. I love that takeaway. It's something super tangible that people can look at. Is there anything that I haven't asked about that our community needs to know about this topic? Wow.

Indu Subramanian:

I mean, everything,

Melani Dizon:

But, like, that we can handle in the next couple minutes-

Indu Subramanian:

Yeah. I'm happy to chime in. So, yeah, do so I think that you know, there are a few things that, regardless of what we're dealing with, so if it's depression, anxiety you know, demoralization lack of meaning in life derailment you know, you name all these big D words, right? That I think people can really hang their hat on. And it's the buffer sort of for I think all of these badness. and I never really understood the importance of this, you know, when I was going through medical school or otherwise. And I think we probably didn't, many of us didn't realize the importance of this when, you know, until we were in the pandemic and feeling disconnected from each other, right? So, I think social support is a huge, huge sort of you know, help for, regardless of what all this is.

And, you know, if you have, if you are isolated, if you are alone, if you feel othered and kind of, you know, sort of alone it's, it doesn't bode well for you because, you know that puts you in mental places where you sort of end up ruminating about bad thoughts and not sleeping well and really thinking, you know, sort of going to these bad dark places. And your focus and energy focus and mental focus ends up being in these rather, you know, you know, negative spaces. What ends up sort of being the antidote to that I think is, you know, sort of finding people that can listen to you not feeling alone, realizing that all of this is so common. You know, it's a human experience. I think that that is just part of, you know, the reaction to a disease like this.

And you know that this is not, you're not alone and that this is very normal, and we have to sort of educate people and empower them to realize that this is not something that they are, you know, alone in. And then to find ways through support groups like you guys and you know,

their loved ones in their community and, you know, if there are things that have given them strength and hope before to lean on those. So, you know, if it is a spiritual practice, if it is, you know, a religious community or a leader that really has always been there, you know, to sort of reach out and go through go, you know, kind of go out of your way. Because people are not going to necessarily knock on your door and say, hey, you're not looking so good.

Let me take you out and do something different, right? You have to identify this and then proactively kind of be willing to, you know, activate some of this. I think social support is huge and I think we've really not focused on that from other perspectives. I think, you know, regaining control when people feel like there's a lack of control in their outcome in their future and they are just sort of you know, in the wind and blowing in the wind and there, you know, it's like, I just don't have any control. I think that's when people really feel the worst. And so regaining that sense of self, self-efficacy, self-agency, being the agent of your own outcome can actually be a huge part of, you know, how, how you're going to do regardless of what you're battling, if it's you know, brain cancer or you know, some, some other, you know, arthritis or, you know, a disease like Parkinson's where the mind and the body are so connected.

And I think we've, you know, really seen and valued that much more in 2022 and these last few years than ever before where we just thought, you know, a little bit more dopamine, a little bit more, you know, tremor control a little bit more you know, gait and balance sort of focus with this and that, you know, is really the sort of answer. So, I think, you know, helping people to find ways to regain that sense of agency through things like lifestyle choices is really something that we've been sort of focusing on wellness kind of approaches. Can I do something that I love you know, exercise or a mind-body practice? And it could just be, you know, dancing with your friends you know, at a salsa club or, you know, going to you know, a Sunday brunch after your church group.

You know, it's going to be very different for each person out there. But really sort of understanding that those things are part of, you know, the medicine and creating a framework for people to kind of thrive around those sort of lifestyle choices. Something that I think regardless of any of these sort of issues that we're dealing with, obviously some things are going to require a pill or an adjustment of something that is a little bit more you know, sort of aggressive management. But I think regardless of what you're dealing with, many of these basic, basic things are something that we should all be incorporating in the lives of, you know, treating Parkinson's patients from day one and giving them a diagnosis of, you have Parkinson's, but it's a very treatable disorder and these are the things that you can do in your life every day to make a difference. That's a very different type of diagnostic kind of conversation than you have a neurogenic disease and take this pill and come back and see me in six months. Right?

Melani Dizon:

Ah, for sure. Yeah. Any, anything to add to that, Greg, or Brad?

Bradley McDaniels:

Yeah, you know, I'll just, I'll just echo what Indu said and one of the things that she was saying, but didn't say it was social prescribing, right? That's one of the things that we've written about recently. And from a clinician's perspective, it is more than, here's your diagnosis, here's your pill, I'll see you in six months. It's how can I help you begin to understand and what do I, what do you need to do to most effectively deal with this new diagnosis? I can't imagine walking into see Indu and walking out with this diagnosis of Parkinson's disease that I know is never going to change, right? That's, that's a traumatic experience no matter how you want to frame that. And I think that I know that many of the PD patients whom I talk to on a regular struggle with that, with the providers that they see, and it, I think that I, I've been just blessed to work with these two who have that attitude of, I'm going to give the patients all of these things that they need.

It's much more than me writing a prescription and having them going and getting it filled, right? It's getting that I have a job to guide you to these things that will help you do better. And if you do these things, your outcome's going to be significantly better. and say it in a loving way, say it in a caring way, and listen to what your patients are saying. And I think that's a message that we can continue to put out there because I don't think it's said enough. And I think that more people hear that, hopefully, they begin to go, you know what, I can incorporate that a little bit more into my practice.

So yeah. I love the term "social prescribing." You know, I actually had somebody show me their doctor. they had gone to their doctor, and they showed me the prescription that was written out and it was exercised. And for some reason, just the fact that that doctor wrote it down on a thing made it feel really different. It's like, Hey, that's over the counter. You can do that. You don't need to. But they, but they wrote it down and they really took that to heart. The same thing for this, like, connecting to a community, finding a friend, like, doing something. You write that down just as much as you write down cinema. And that's, that's changing the way we talk to people. With Parkinson's.

Bradley McDaniels:

Melani Dizon:

Absolutely. Yeah. What about you, Greg?

Greg Pontone:

Yeah, I just want to sort of make a comment about how we've undervalued social contact and social connection. You know, I think the pandemic really unmasked that. And you know, really if you think about it, there's a classic series of experiments by Bulb when they had these little monkeys, the little baby monkeys, and they would have this sort of fuzzy mother that they could cuddle with, and they would feed them both the same amount, right? Monkeys who



could cuddle with the fuzzy mother and the ones who couldn't. And what they found is even with the same amount of food and nourishment, the monkeys who couldn't cuddle, they failed to thrive. And so, you know, I guess my only point in saying this is that don't isolate yourself. You know, the tendency when you're not feeling well is to withdraw. And that's really just going to start a snowball effect, a further decline.

We, you know, regardless of how you quantify it you need to have contact. And it can be almost anything. You know you heard some examples. It's what's meaningful to the person, but that social contact is really something that you cannot do without at least not without, and, you know, thrive and optimally function. And so, you know, whether you like to be in groups or whether you like to have one-on-one contact and whether it has to be prescribed if it's deficient you know, is going to vary from individual to individual. But I think that there's physical health outcomes that suffer when it's not around.

Melani Dizon:

Yeah. Well, I really appreciate it, this is truly the dream team. I wish every single person could see all three of you in there, in their road with Parkinson's. But hopefully, they will take a lot from this and start talking to the people in their lives about these topics and talking to their doctor, and starting to take action to help themselves live better with Parkinson's.

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