

**Health Disparities and Parkinson's:
Cultural Context**

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Davis Phinney Foundation

Jenna Deidel (Director of Programs and Outreach, Davis Phinney Foundation):

We're so lucky today to be joined by a couple of experts who I would guess might be pretty familiar faces to many of you here in the Parkinson's community. Dr. Andrew Subramanian is a clinical professor of neurology at UCLA, and she established the movement disorder clinic at the west Los Angeles veterans administration. And is the director of the Southwest pederastic center for excellence in Parkinson's. And Dr. Greg Pantone is the associate professor in the both departments of psychiatry and neurology at Johns Hopkins university school of medicine in Baltimore. He's an attending psychiatrist in the geriatric and neuropsychiatric division and is the director of Johns Hopkins Parkinson's disease, neuropsychiatry clinic. And somehow they're both making time to talk with us today. So we're really grateful that you're here and really excited to dive right into this topic. So I think into, if you would just kick us off by setting the stage and sharing kind of helping us define when we talk, when we hear this, these words cultural context, what does that term referring to? What does it mean? And maybe even back taking it one step back, what do we mean when we talk about culture? How do you define that and how are you thinking about it, you know, in this work?

Indu Subramanian, MD (Clinical Professor of Neurology at UCLA and Director of the Southwest PADRECC Center of Excellence in Parkinson's):

Yeah, so, I mean, I think even taking it back a few steps, so I've been a Parkinson's doc for about 20 years, and I think, you know, historically we've really been serving a certain type of demographic. Well you know, I think a lot of the pictures that we have out there of who gets Parkinson's, what I learned in medical school was a sort of white, you know, sort of man who, you know, went through the stages of disease and, and became more sort of immobile. And, and these were sort of the images. It was like an older man who was you know, Caucasian. And so I think, you know, just contextualizing, you know, who gets Parkinson's in the world has really I think been something that we've been trying to reinvent and to rebrand a little bit, because I think because of these sort of images, a lot of patients, like if, if you look at somebody like me, there are people that look exactly like me that comes to clinics every day, complaining of symptoms that are Parkinson's symptoms that get told that they're, you know, crazy, that it's all in their head, that they have, you know, they get put on medications for anxiety or depression or something else.

And if they're told that they have functional symptoms and really the disease is the diagnosis is missed because of, I think this sort of demographic idea that we've had historically then sort of

catching up to 20, 21. I think we've seen just sort of the, the landscape of medicine being practiced in a country like the United States where there's really been a lot of inequalities inequities in care, disparities and care. And I've just been really open, open my mind to just how much we have not been serving many populations well in this country, as well as outside of this country in the world. I came to find out that, you know, there are populations in the world that have no access to even Carbidopa-Levodopa in Africa and that's mind blowing to me, what are those patients being put on for a highly treatable disorder like Parkinson's disease.

So I think we've really sort of connected globally as a community and really been thinking a little bit outside the box of, you know, who are we serving and, and who are even you know, we capturing in terms of the sorts of studies that we've been doing. A lot of the studies that we've done time and time again, when you look at demographics and a lot of these studies has never even had to report demographics of patients in gender and, and you know, race a lot of it's just still, it's the same white affluent males who were married. And so when we come up with prescriptions for what patients should be doing to help themselves with their Parkinson's disease, even in open-minded spaces, like the wellness space, which we'll talk about in a minute, I think we've really been sort of very narrow in terms of the type of prescriptions that we've been able to think about giving our patients.

So if we think about, you know, me at UCLA running a study in a gym, people come in, I'm doing, you know, 30 minutes on a treadmill you know, get their heart rate up to a certain amount. And then we use that prescription and say, this person should be doing this type of prescription 30 minutes a day for five days a week. And we apply that to populations across the world. This is really something that may not be terribly accessible. Similarly with diet. When we think about things like, you know, we give talks about eating every color of the rainbow in a salad, and, you know, we've had dieticians, I had a dietician come into the VA who gave a talk like that with beautiful pictures of salads and all kinds of colors. And I was looking at the audience thinking, you know, I know a lot of these patients live in parts of the city where, you know, the closest food is really going to be at a liquor store or, you know a store where a lot of it's pre-packaged, you know, if they go to the canteen at the VA or the store at the VA, it's really going to be, you know, nothing that looks like those vegetables.

You know, so I think we just have to really think outside the box in terms of when we're giving people an idea of how to empower themselves and how to really think about these prescriptions, you know, are they able to access this? Who are they in the world? Where are they living? What are the barriers for them in their everyday lives? And then how can we, you know, sort of really meet them where they are and help them to sort of thrive in this sort of concept of wellness, which I'm happy to, you know, explain a little bit more about, cause it's been a passion of mine and, you know, Greg's as well. You know, so we can talk a little bit about

that, but that's sort of a roundabout way to sort of put a framework. And then, you know, I know that Greg has some ideas also about the definitions of culture.

And I think, you know, they could be different depending on what dictionary you look at. But I think what we're talking about in this sort of space is really the intersectional framework in which a person you know, comes to see me with who's living with Parkinson's disease, that person in their environment, in their world, you know, be it race, which I think is a very small piece of this gender, which is another piece of this, which there are huge disparities in that you know, what their community looks like, what their you know, maybe sexual preference, what they're different types of things that may affect them every day look like where they're living, what zip code they were born in. All of these things actually have a huge impact on, you know, what, what ends up happening in their disease, including maybe trauma that they may have faced in the military, for example, with Parkinson's. So I think all of these things sort of in my mind kind of frame the sort of cultural context, and maybe Greg can speak to that a little bit as well.

Gregory Pontone, MD, MHS (Director of Parkinson's Disease Neuropsychiatry Clinic and Associate Professor of Neuropsychiatry and Behavioral Sciences, Johns Hopkins University):

No. Yeah, I agree. And do I think that a great description, you know, when I think of culture, it's, it's bigger than the individual. So you're going to be interacting with the individual has Parkinson's, but you're also going to be interacting with their family and to some degree their community, right? Because they have to live and perform their activities of daily living within a community. And so, you know, culture is sort of the knowledge and rules and ceremonies religion, sometimes that are passed down for generations, people live within that context. And the disease has maybe a different meaning between these different cultural contexts. For instance, you know, there are cultures that really value individualism and there are other cultures that are much more about inclusion and harmony of, you know, between individuals. And so I think that's really important because, you know, you may be trying to achieve one goal with your sort of cultural values that isn't necessarily consistent with theirs.

And the same thing when you're working with care partners or families they may have one conception about how they want to care for their loved ones. You know, maybe in some Western cultures, it's very transactional, you know, we're busy, we're working, that's the expectation in our culture. So we want to outsource the care, right. And, and the individual is okay with that because they said, Hey, I've never, I didn't never wanted to burden my family. Whereas other cultures are that would blow their mind. They're like, no, no grandma was always going to live with us and we're all going to contribute and, and doing it any other way is, you know, not within their vocabulary. And so I think I failing to account for this is really gonna settle for a less than optimal fit for your intervention. Even the way we express distress, I think is somewhat culturally bound.

So I'll, I'm going to give you a little personal piece of information. I come from an Italian and German family. So that German side is very stoic. Like you just don't complain. No one wants to hear it. And the Italian, everybody knows if you're hurting, right. You're moaning and whining and you're pulling other people in to help you. And so there's really a contrast there, and I'm not saying either one is better or worse than the other, but there's clearly a different expression of distress and it's acceptable in this culture and not so much in this. So, you know, yet you knew when the wine and my family and not when not to so same thing here, you know people, families, and within their cultural context are going to have a different level of acceptance of even the reporting of symptoms and how, and how you you know, express your, your sort of distress within the same disease.

Jenna Deidel:

So the short answer is that culture is everything really is that culture is the way we do things the way we think about things, the way we express ourselves, the language we use, all of that kind of stuff. And it's influenced by so many different things where we live, where we come from, our families are all of those things. So it's really complicated. And also we all, we all can relate. You know, I would imagine, as you were just talking about your own experiences and observations, you've made, there's probably folks here who said, yeah, I heard that salad thing and thought I'm never going to eat. Like, that's not how I eat, or I've heard that exercise thing. That's not how I move or, you know, I, yeah, I don't talk about my pain because we don't talk about pain in my family. So those kinds of things now, you know, we all can imagine, okay, that's how that feels in my life.

So as folks who are looking at studying this and trying to help us get better at doing this both for ourselves, but also as care providers or as educators as organizations it sounds like you have to look at this from a couple directions. One is noticing where we're kind of doing this we're ships passing because we're saying one thing, and it's not landing with the diverse the diversity of thought and the kind of people that we're talking to. And so really noticing how that's resulting in, in poor, really kind of poor care or poor quality of life, because it's even though if it's, even if it's tested and good advice, if it doesn't mean something to me and I can't integrate it into my life, it won't really help me. So I'd love to hear a little bit about those two sides of the coin.

And I wonder if India, if you want to talk a bit about this idea you've shared with me around that idea of meaning and joy and sort of how you can, how we connect and why does that matter? You know, I think especially in, you know, probably our, our culture of the U S and thinking about medicine medicine can feel, can literally have that idea of feeling. We use the word clinical to describe things that feel a little less emotional and with that comes from that place, but this is emotional and it does require, you know, meaning and joy and things that may

and matters to resonate with people. So I'd love to hear a bit more about how you've been thinking about that. And for both of you, and I'd love to hear about the flip side of that, how are you seeing, you know, when those ships pass what's what's happening, what does that actually end up looking like? And what are those disparities start to look like? So kind of shift us into that conversation. Yeah.

Indu Subramanian:

So I think just backing up, you know, I have a background in yoga teaching mindfulness teaching, I've been quite open-minded. I have a background in integrative medicine, which is really the medicine of, you know, Western medical approaches and the intersection of that integrating some of that with other approaches, which include traditional Chinese medicine. I have the mind body approaches, kind of a holistic health kind of idea. I also practice at the VA there's this sort of real emphasis on what we call whole health, which is sort of this approach of having the patient in the middle and a lot of different things around them, including social connection, which I think is huge. And as part of this cultural dialogue, you know, who are the people that people connect with who are their social support networks and who is in their family that really would, can be engaged to kind of help them along the trajectory of disease a number of other sort of lifestyle, things that we try to encourage people to do in this holistic model with the sense that wellness is really this sort of concept that we can, as people in the world pick lifestyle choices every day, and have some sense of control over the outcome of, you know, how we're going to do be it in Parkinson's disease or any other sorts of even in aging.

I mean, I think there's ways to think about a number of things that may you know, help you to, you know, pick ways to live in a more thriving manner and really get to a place where you feel in control of your outcome in a holistic way. So those include things like exercise, which I know the Dave Spinney foundation. I love giving talks for you guys, because you guys believe that exercise is medicine, but diet, sleep is huge in this dialogue social connection. We mentioned the mind-body approaches and in the cultural context of the mind body approaches, actually, you know, a lot of what we talk about is, you know, can you meditate for 20 minutes a day using this app? And we can study this and, you know, give you these prescriptions. But one of the beautiful things about mind body approaches is that they sometimes include things that everybody's doing in certain cultures every day that brings people joy and meaning.

So that could be prayer, for example, you know, or getting together and singing in a choir in a church. You know, that brings you some meaning and a cultural context that, you know, may help you from that mind body space. So I think sometimes when we define these lifestyle choices and this wellness kind of realm, we sort of need to really think about the person in their environment and that cultural context. And one of the things that I've really been doing more and more, I have an interest in palliative care thinking about how people not only, you know, live you know, in a thriving manner, but also as they tend to start developing more symptoms,

how can we support them into, you know, sort of later stages in disease and support their families. And when we talk about those palliative care principles, a lot of it is around what brings people joy, what brings people, meaning what defines health and quality of life to a certain individual.

And so I think without talking to people and really establishing that rapport we're really kind of missing the boat, right. We're having those two ships collide, like not, not meet, but actually pass in the night. And, you know, so for some of my patients, it might be, you know, if they can't play with their granddaughter, you know, on the floor with their toys, that really is something that they're missing out. It might be, you know, trying to play golf every day with their best friend who lives next door. It might be climbing Mount Kilimanjaro for somebody. So everybody is very different. And I think, you know we have to really think about, you know, what brings us joy, what brings us meaning when we wake up in the morning, what do we look forward to and help, you know, as healthcare providers.

And I don't just say that as physicians, I think sometimes, you know, that team of people beautifully Greg and I have, you know, this resonance, we kind of are drinking the same Kool-Aid these days, but often people think about just their neurologist does the only point of care. But I think, you know, really expand that to support group leaders possibly, or, you know, yoga teachers or a psychologist that might meet them, or, you know a marriage counselor, whoever you know, maybe physical therapist in, in their community, somebody who really can connect with them and understand kind of how to build in these pieces every day to make life more meaningful. And so that, that if it's meaningful to you, you feel like somebody is listening to you and helping to pick things for you. Then I think it really allows a report to be built.

And then it breaks down these sort of issues with trust that really we've seen a lot of, you know, we have huge communities that feel like medicine and modern medicine and healthcare is not serving them at all and maybe harming them, you know? And, and I think we really just have to understand where that's coming from. I think one of the first places is just to have dialogues like this and say, you know this is where that mistrust comes from me. It's because of, I read this story or I know my granddad, you know, was part of a trial that, you know, really was not done well. And I feel like, you know, there was a real abuse of my community in this sort of setting or whatever, but I think we just need to really break down sort of the barriers that are in place, obviously you know, and, and try to sort of work from the ground up to help each other, understand each other dialogue more and then meet people, honestly, where they are, because if we don't do that, a lot of the day-to-day studies and the research that Greg and I are doing that we want to help a population, the whole population of Parkinson's patients.

We're really not, we're missing so many key people that we really want to be serving. And I think it makes our jobs less sort of fulfilling as well. Then it's frustrating because, you know,

Greg was telling me that he works in a city of Baltimore and is trying to recruit people even for care or for, you know studies. And there's such a small population of the people that really are representing, you know, the true population of a city like Baltimore. And maybe Greg can speak a little bit more to that.

Gregory Pontone:

No, I, you know, Andrew you're right on point here, this is you know, meeting people where they are to me is about coming to their culture rather than trying to impose your cultural beliefs on them. And I think that's where a lot of the miscommunication and comes from is you're really at cross purposes. And so, you know, when we look at you know, people in their community, you know, you were talking about whether it's yoga teachers or expanding who interfaces with people, suffering from a disease. I mean, for some call serves, the religious leaders are going to be really important, you know, for other cultures, not so much, you know, there's going to be more more secular infrastructure. But I think we really have to understand that because sometimes the people that aren't coming to specialty care, aren't going to be attracted to that care by the, the normal agents providing that care, meaning you're going to have to look at community leaders, either secular or religious to identify these people in the first place.

You know, and then I think you have to show them that your purposes are in synergy, you know with their values, you know, what do you value? And can we bring this to you in an acceptable way? You know you know, some people see certain ways of going about treating illness as a weakness. You know, it's hard for them to accept that type of intervention, but if, for instance, if it comes from a family member or some other direction it's more acceptable. And I think we really have to accept that sometimes, you know, medicines have a meaning outside of their intended purpose. And I think we really have to at least make the effort to understand that. And really getting more to induce point is sometimes it's more important to understand the person with the disease than the disease the person has, you know, into, and I, you know, could literally write a book about Parkinson's, but when you're treating people, I think it might be more important for us for the entire healthcare team to actually have a better understanding of the person and then the disease second, because if it doesn't fit the person you're at an impasse.

Jenna Deidel:

Absolutely. And I'm always struck a bit when we have, you know, these discussions around health disparity. So often we come back to these common themes of you know, communication trust and, and really sort of an overlying issue with that is it's time. Right. And things like that. And so knowing that it, it, it does, it takes a fair, a fair amount of time and have been investment that isn't always allotted for, for some of these you know, appointments and things like that. But I would love to hear, you know, we've, I think you've both done such a wonderful job of helping us understand, you know, what it is, what are we talking about when we think

about culture how is this showing up? Why, how is it causing problems and also sort of what potential it has to, to bring more, more meaning and to actually improve people's quality of life and care.

I would love to hear some more of those, those examples where you've seen it work, or you see the potential. So, you know, as, as you're doing this work, the desired outcome is that we, we better understand this. And we start to weave this into our conversations, our practice, and that's, as you said, that's going to be in support groups. This is one-on-one. This is, this is across all folks that are, that are caring. And, and part of that, that system that helps people live well with Parkinson's. And even with ourselves, our conversations with ourselves. So what are some questions that you ask? Yeah, Greg, go for it. Jumping right in.

Gregory Pontone:

I have to have to confess, I poached this from the chat. So I've been watching the chat.

Jenna Deidel:

Great. Let's

Gregory Pontone:

Do it. So this was one of the early chat questions was about someone who is newly diagnosed. And I'm gonna answer the question a little tangentially. I'm gonna answer it within the context of culture, because this is, this is a common problem. When you first diagnose someone with Parkinson's disease, you you know, it's still a clinical diagnosis. I mean, we have fancy new dat scans and technology that support the diagnosis, but at the end of the day, it's still a clinical diagnosis. You walk into your neurologist office, you tap your fingers, you stomp your feet. And then 15 minutes later, you'll walk out with a life-changing diagnosis, you know, and for most people that's very unsettling. You know, they want to see, they want to see something tangible, right? Show me an x-ray show me something that proves to me in a tangible way.

I have this, you know neurodegenerative disease. And so you now overlay culture onto this, right? There's I sort of told you about two cultural extremes, right? The Italians, which are a high expressed emotion culture, and the Germans who are a low expressed emotion culture. Right? And if you do the wrong thing in that culture, you know, you don't get what you want, right. You're not gratified and emotionally. And so imagine this, you have someone in a German culture who comes out with mild initial symptoms of Parkinson's, but with high expressed emotion, and into actually said this, right at the beginning of the talk, they're going to blow you off. They're going to say it's psychosomatic. And you have, and especially if you're a young woman, right, you don't fit that old white male. Then you're coming out in a low expressed emotion culture, you know, really worried about your symptoms.

And they're not, you know, remember we don't have an x-ray that can show you, you're going to probably go down some rabbit holes before you get the care you need, because you're out of sync with your cultural values. Okay. So as a clinician, this is at this brittle first stage, you know, this delicate first stage of diagnosis, you really have to understand not only the patient, but the sort of system, the cultural and, you know, family and community support system, they live within. And in terms of getting them on track. Cause here's the other scenario is you have the person who, you know, might be in a medium or high expressed emotion culture who just really isn't that distressed. Right. They have low expressed emotion. And so they have Parkinson's, but they're so understated in this particular culture that they go five years on treated, experiencing disability. They don't need to have, if they would just embrace the diagnosis or maybe they could get five different opinions. And now they're getting treated for chronic Lyme when they really have Parkinson's. And so I think we really have to pay attention because in that early stage missing can have consequences. And I think that's going to be even more true when we have disease modifying therapies where every minute counts in terms of the number of neurons we're going to be able to spare save.

Jenna Deidel:

Yeah. I mean, that's, that's a lot to be taking into consideration when you're sitting in front of a patient that you may or may not know very well. And I, you already suggested the idea that family and friends, you know, and, and sort of the, the, the network, the social network, you know, is, is a really key piece of this entire concept and actually sort of the, you know, the overcoming or the reinforcing or the, whatever that's going to be, that's going to lead to that better care. So you know, I'd be curious to hear, you know, how, if, if we're someone who's maybe in that seat, you know, we're a care partner or a family member, or a friend who's noticing something you just pointed out, you know, someone who's, you know, that, that sort of mismatch between what's happening clinically and sort of their culture. Are there ways that we, as, you know support systems can, can help with that. And I'd love to hear from, from both sides, you know, what, what sort of thoughts you might have for that?

Indu Subramanian:

So I think you know, one of the things that, there's a few things, so one of the things that's complex about Parkinson's is that there's, you know, these motor symptoms that most of us is neurologist. That's what we focus on. So if you're looking like you can walk down the hall pretty safely and you know, you're not trembling too much, and we tweak your cinematic or whatever, then we've done a good job, right. And the 15 minutes that we get to see you every six months, but there's this huge non-motor burden that is lurking under the skin, right. It's like the skid and face that is huge. It's you know, things like constipation, things like autonomic issues, things like bladder issues, things like pain, things like you know, that, those things, but then there's this huge mental health burden, but that I think has really gone really under sort of valued under recognized.

And we really have done a disservice, I think, to our patients by largely calling it this movement disorder with motor symptoms. And we, you know, again, with those drawings of the white, you know, male that's really, you know, having more and more motor issues in these pictures, really sort of projected a very nice idea of motor symptom burden. And if we've done that well you know, that we've done get a pluses neurologist, but then what really affects our quality of life. And most of our patients honestly, is it's non-motor burden. And then, you know, enter things like pandemic enter isolation and loneliness and cultures where we are, you know as people age, they tend to not want to be burdens, tend to sort of you know, isolate themselves sometimes. And, you know, you have this huge non-motor burden. And then this mental health burden and, you know, reg and I spent a lot of time thinking about, you know, what should we be doing proactively as we follow our populations that we love that we're trying to help, you know, through zoom you know, sort of meetings and whatever we can to kind of keep people safe in this sort of a timeframe where we've not been able to, you know, drizzle in these in-person support in person you know, sort of physical therapy classes in-person, you know, large group exercise classes, yoga classes, support group classes that we've really enjoyed you know, sort of helping connect patients to each other in person we've been able to, you know, sort of help people you know, through hugs and touch and, you know, smiles, we don't even do that in our offices now, it's all, you know, through this type of screen or with masks on.

So, you know, people are really, you know, suffering and I think the mental health burden historically has been stigmatized. Hopefully with the pandemic, we can break down those stigmas a little bit and really get, you know, the care where it needs to happen. I think that the sense that, you know, in my 15 minute visit in my ivory tower wearing my white coat, that I'm really gonna help the holistic health of my patient for the next six months is, is crazy. Right. I mean, why, why would that make sense? So we have to think about other ways other multidisciplinary team members that we can use engage, but also how can we engage the community? And when we've been looking at, you know, our social isolation data, which is huge, you know, loneliness in Parkinson's patients is as bad for you as being able to exercise you know, seven days a week for 30 minutes a day is good for you.

So it's a huge, you know, negative. And so if, how can we help patients to find ways to engage themselves in their community? And I think it, again, boils down to that cultural context of where the person's living, who the people are that surround them, and they may not even have realized how disconnected they are from these things that they may have really brought them joy. And in the chat we're seeing, you know, tons of siblings that are trying to help their family members. And unfortunately, you know, the way that this disease works is that people, you know, get symptoms. They tend to sometimes be in the non-motor realm, they're embarrassed. Sometimes it's not visible to people and they feel like they're a burden and they tend to isolate themselves. And that's just part of this disease. And we have to really normalize, you know education, empowerment, you know, normalize the need for a support network to have a

buddy that comes in with you from diagnosis that supports you and, and not just sort of wait until something happens.

And that's when somebody, you know, suddenly needs to engage a family member because they can no longer drive or they can no longer, you know fill out some forms at an office or something that, that sort of rapid need to then establish rapport for us, as clinicians with family members have been kept out of the picture is very stressful. And the family members also feel like, Hey, you know, I would have been here for you from the get-go and understood this disease, you know, but you kind of kept me out of that sort of circle. So I think, I think we really have to think about how to support people. And Greg and I have talked about almost as you might visit a physical therapist on day one of your diagnosis, maybe, you know, you have a psychologist or a social worker or a social, a support group leader, network, whatever, or even a mentor you know, a person who may have had the disease for a little longer than you as a patient or a buddy health coach. I mean, there's many, many ideas that that could be engaged with people who may be in the community who can hopefully do some of this work to really help people understand the things that they're gonna need, provide them some, some framework you know, some tools that may help them thrive, you know, for, you know, the long run. I don't know if you have any other...

Gregory Pontone:

Yeah, I do. So another one that kind of fits into your conversation there, that's in the chat. I peaked again. And they said, there's this feeling sometimes after diagnosis of shame and guilt. And I guess the question is how can we take the individual's cultural identity and help facilitate acceptance of the disease and, you know, acceptance by the individual, but also acceptance by the individuals, community, and family, because again some cultures, your utility to the culture is defined by your ability to perform certain duties. And so becoming disabled in any way you know, physically incapacitated, mentally incapacitated is a foible. It's a weakness and it generates shame and guilt, right? Even if it's inappropriate, right, you feel guilty because you don't meet the cultural ideals anymore. And so I think that's a big reason for sort of denial of symptoms and denial of symptoms often leads to poor compliance or noncompliance with treatment.

Or like I mentioned before, we have people who are in denial for the first leg of the disease, and they missed the opportunity to experience a better quality of life. And I, I think in most cases, it's not enough just to intervene at the level of the individual. You really have to understand their cultural values and then work with them and their family and ideally their community, which gets back to what indu saying about educating, not just the individual, but the individuals, family, and community, because, you know, this is something that could happen to any of us, right? We could develop this neurodegenerative disease and it alters certainly our ability to do things, but it shouldn't alter our value to our family or society. And now, and this is

going to vary by culture because you know, some of the Western cultures and I'll keep going back to my German heritage, if you're not useful, you're not that valuable.

And I mean, that's just the way it is, you know, and I mean, look, that's a hard take on it, but there very much is a, it's a utilitarian culture. Whereas, you know, if you look at some of the more sort of Eastern cultures, there is a value for aging, you know, they have like a sort of, almost like a reverence for ancestors. And, you know, as you grow old, you are a repository of the memories and beliefs of the entire family, and it doesn't have anything to do with the merits of your achievements. And so, you know, this is going to be really important based on your culture to understand where the shame and guilt is coming from in overcoming that so that people can accept their symptoms and go on to have the best quality of life possible. And I think if you ignore that, you're ignoring a significant piece of what will be in what, what will dictate quality of life for the individual

Jenna Deidel:

I'm hearing, you know, really that we focus a lot about. And you know, the, the individual and maybe the care partner and the clinician, right, as you said, the 15 minutes in her white coat, and then there's this, there's the, the real world that exists around that and sort of the many gaps and, and, you know, the flip of that, the opportunity for support in the in-between there. So I'm hearing a lot of suggestions here around how those things might change or, or, you know, be looked at differently in order to sort of counteract these really complicated human emotions of denial and shame that we know, particularly with someone living with Parkinson's delays treatment and, and, you know, affects how, how, you know, what your symptoms are going to kind of look like. So the flip side of that sounds to me like suggestions of, you know, building confidence, building finding community.

We have a question in here around about that, that I write suggestion of like a mentor and a buddy, you know, we, we have an ambassador program that's available on our website where you can look through over 70 people who have volunteered mostly as people living with Parkinson's to sort of take that role of mentor buddy. But would also love to hear in your experience of how, you know, have you had success or have you observed someone successfully navigating that road from coming really from a place of denial and shame, and then sort of thinking, you know, pivoting that and saying, I'm going to build my confidence. I'm going to find my community. I'm going to find my mentor and a buddy, particularly in a space, you know, in this idea of, of context, they, you know, kind of putting all the pieces together. So this is what's meaningful to me. I need to build my confidence in my community in order to live well and to move forward. Have you observed any great examples of that, or do you have suggestions for folks of how they might, they might do that or, or help someone through that experience?

Indu Subramanian:

So I'm excited to, you know, I'm a neurologist at UCLA and I run a the center at the VA as well. I'm a colleague of a patient of mine who goes by the name twitchy woman has arranged this women's support group. And it's really you know, been amazing and they've sort of does design this mentorship program because I think they saw a need. They've been trying to pair people with like interests or like geography it's become an international kind of attended program now because of the, the beauty in some ways of tele-health, which is, I think a silver lining of this horrific, you know, pandemic that we've all been in. But I think, you know, there's a lot of ideas using modern technology, possibly social media possibly I think, you know, the, the sort of different types of platforms like this one, for example in which you can kind of you know, participate in the chat and feel connected to sort of people that you're, you're sort of watching live.

So I think there's a lot of ideas. I do think that we have to really think outside the box. And so you know, who are the trusted leaders in some of the communities that we are not serving? So it might be religious leaders. I was talking to some African-American you know colleagues of mine and, you know, the hairdresser the sorority sisters, you know, people that, you know, are really the framework in which people thrive. I think we have to think outside the box you know, and, and, and so think about your own culture and who really the people are that you you know, sort of bring you sort of joy and meaning and stability, or, you know, that you really look to. And I think for each of us, it's, it's, it's different. Additionally I think, you know, sort of the concept of, of getting a diagnosis like Parkinson's and then sort of, like you said, you actually, you, you, you said it very well, Jenna you sort of have this diagnosis it's has negative connotations, or you spend a lot of negative energy sometimes, you know, understanding it sort of like there's, you know, denial at first, and it's almost, in some ways I've spent some time looking at grief literature sort of like the stages of grief where you go from denial to acceptance.

And I love the book by David Kessler that just came out last year in the pandemic, which is, I think it's called finding meaning, but he actually takes that sort of grief you know, sort of architecture of somebody, maybe a loved one passing away. And then this sort of last stage is actually been finding meaning or purpose from what's been what's happened. And so I think that if we can help our patients to reframe and really pivot that sort of negative energy and sort of the sort of you know, not accepting the diagnosis and I've seen people literally pivot into some very positive way of spending energy, connecting sometimes becoming activists, sometimes becoming advocates through some sort of, you know, framework of, for Parkinson's, or maybe even for some other causes, it could be global warming. It could be, I don't know, birdwatching, whatever, but really sort of reframing in the sort of societal kind of meaning context to really then bringing in energy and realizing that they actually do have something to give and really something really meaningful to give.

And, and I've seen patients who literally have come in to see me not been in a great sense of health, not been in a great mental framework before they got the diagnosis and what with the diagnosis have actually been thriving and in a very different energetic state of being leaders of support groups or leaders of, of things that are really amazing stuff that's happening in the community. So I urge people who may be isolated out there to you know, look at some support groups out there there's a ton of I think amazing, amazing connections that are even international with the world, Parkinson Congress groups the PD Avengers, for example, which are some amazingly dynamic people. The book ending Parkinson's disease has a lot of things that are very low hanging fruit, you know, of things that we can all try to do to really make a difference for this diagnosis.

And I think if we can find, you know, bite sized pieces, maybe working with a therapist, maybe working with the support group leader, maybe working with a buddy or a mentor, we can kind of find ways to engage ourselves every day to feel like we're kind of still contributing. And the last thing I would say is that I have family members that literally come in to see me with my patients and you know, because of my urging of the patient connect with the family and to go to these events and really to include people in the diagnosis of said, you know, I really miss my mom. You know, I, because of this diagnosis, she sort of hid from us and she wouldn't tell us what was going on. And we just wanted her there in some way. And now, like, I feel like, you know, with trying to open that door and having really reconnected, you know, she's such an important part of our family and it's been something that we've all been missing.

And I think, you know, for patients that might be out there, even caregivers that have isolated sometimes as a care partner, as a couple, you sort of isolate yourselves from the family, cause you don't want to burden them or be visible you know around, you know, spaces and events and things, and people invite you to things and you say, yeah, no, thank you. I'm not going to come to that wedding. Or I don't want to come to that Sunday. Supper really think about that because I think that, you know, we really don't realize how important we are to the people that love us. And sometimes just rethinking about that and say, well, maybe I'll give it a try if I hate it. I'll I can leave in an hour. If I hated I can leave in 15 minutes, but let me just show up, let me put my shoes on, get up the door, show up with a smile. And then if, you know, if it doesn't work out, it didn't work out. But at least I tried. And so I think sometimes we just get in these sort of head spaces where we feel like we're not important that we're we're, we, we, no one would miss us, but really the whole time people are missing us. And so I

Jenna Deidel:

Really want you to think about that.

Gregory Pontone:

Yeah. I think that's a great point. And do I think so many times, you know, whether it's Parkinson's or cancer, when someone is diagnosed or labeled with a disease, you almost feel as if you're a part from your group, apart from your culture, right? All of a sudden you don't belong because you have this malady and it really is about re-integrating. And I think, you know, if you take a parallel from culture, you know, people of the same culture usually share a language or religion foods, right? It's they share it's shared experience and like it, or not, one way to leverage the experience of Parkinson's is it's a shared experience. So now you're part of a new group and you know, there's strength in numbers. And I think, you know, you can look and say, these are people just like me, you know, they're people who have a disease, not the other way around.

And that was sort of my comment about it's more important to know the person with the disease than it is the disease the person has. And we really have to flip the script for people and say, you're still part of this community. Right. And we have to reintegrate you. So yeah, you freaked out a little, you got this diagnosis and you felt like you were other, but you're not really, you're still us. And I think that's really the message here. And I think that's the role that foundations play, you know, the Davis Phinney foundation, you know, you guys say every victory counts because every victory is someone saying, okay, I got diagnosed and I felt like I was over here, but now I'm right back in the herd. And every person who comes back over here in the herd is sharing their experience of sort of overcoming that part of the disease. And I think that's really what we're talking about. And we have to do this in a way that's sensitive to people's culture so that we're not imposing our values on them. We're coming in, fitting their values the other way around.

Jenna Deidel:

That's awesome. And really what I'm thinking about as I'm listening to this really great advice and really encourage really sincere encouragement. I mean, it's, I know both of you care so deeply about the Parkinson's community and it's so evident as you, you know, kind of give, give this real call to action to say, you're still part of, you're still us. You're still part of us. And what I'm really hearing is sort of this two-sided thing of one you know, sort of this idea of inclusion in the Parkinson's community. So the Parkinson's community is a strong community. And if someone is, is willing to step into that community often, they're greeted with a pretty amazing group of people who, who are, who are quite inclusive and quite welcoming. And, and one way that, you know, I think we can call the action hearing today is for those of us that are building that Parkinson's community, we can further make it welcoming inclusive by taking the consideration and really listening to where someone is coming from and sort of the culture that they're that bringing in, what matters to them.

So that's one, one piece I'm taking away. The other one though, is sort of the visibility in, in the rest of our life. So we want to, we want to encourage that inclusion into our Parkinson's

community. And also we're, we're much more than our Parkinson's. And so the showing up into the rest of the life, that visibility has two sides. It's what you just encouraged us in do to say, I'm just going to go, I can leave in 15 minutes if it's terrible, if it's as terrible as I'm making it out into my head, guess what? I can also leave. But it's also sort of the space that someone is walking into, right. And sort of creating, creating space where it's not hopefully riddled with stigma and riddled with challenges for someone who is, you know, moving through the world a little bit differently.

So that's, I hear also that call to action, not just to the person living with Parkinson's, but to, as you have said, the family, the community around them and really sort of this, the allies and the advocates. So as advocates yourselves, I would love to hear a little more like what is the call to action for those of us who might identify more in that space of ally or advocate who are out there trying to make it less scary to show up and to create avenues for visibility that are, you make, you want to stay longer than the 15 minutes. Cause actually it turned out to be great. What are some ways that you can, you know, you might invite us to, to, to make safer spaces for people living with Parkinson's.

Indu Subramanian:

So, as we mentioned, I think at the beginning about the cultural context I just wrote a gap's paper for women with Parkinson's and, you know, it's like, there's so many intersections of people that are very different than what we maybe have thought because those, you know, the other nine 99% of the people that show up in my clinic are not that person. But you know, when I see women, for example, who take on so much caregiver burden, they don't want to get care for themselves because they're too busy, you know, taking care of their kids or their, their spouse, honestly still, or they're, you know and, and women that our value is in who we're taking care of. Like, that's what brings us value in society is, you know, can I still cook dinner for my husband? Can I, you know, play with my grandchildren and babysit them?

So my daughter can go to this event or, you know, can I still take care of my mom with Alzheimer's? And I still have Parkinson's, you know, in my fifties, this is what brings us value. And so when we don't have that, we can't do those things. It really does put us in a place of shame or, you know, we're less than, or whatever. So I think we have to be honest about, you know, what each of us brings to the table. You know, my, and if I was a, a woman who was young, you know, who's a lesbian, it's very different, right. Because then who was my partner, you know, maybe different and who's going to be able to care for me in that community may be very different. And so you know, eventually so I think we have to think about the person who's before as you know, healthcare providers and really I think it shouldn't just be an assumption because I was born in India that I, you know, look like this at that, that, and I'm a Hindu on paper that then I would want to, you know have these 10 things.

You know, if I ended up in, in a situation where I was, you know on a ventilator, you know, there should not be an assumption. There should always be an open-ended conversation with people to really understand who they are, what brings them meaning what, what is the quality of life that they, you know, and what brings them really, you know, purpose and, and quality for them in their lives. So I think that's really important is to make no assumptions drop our assumptions. When we think about safe spaces, I mean, I've thought a lot about this from a yoga and mindfulness context, because, you know, sometimes people don't feel comfortable meditating with people that look different from them. And if you are, for example, somebody who maybe African-American and you have, you know, a historical racial, you know, sort of burden of 400 years of oppression, you may not feel comfortable in a place where, you know, everybody doesn't look like you.

And so I think we, we have not in medicine really understood this well, we are not part of, you know, some of these dialogues, we don't read the books that we should be reading. It's not part of a curriculum. I've only recently opened my mind to some of these things. And I think we have to really provide options. Maybe it's be on a zoom with your camera off. You can just partake of what you want, but you don't have to be visible and that's okay. You know, or be in the back of a yoga class and be able to arrive in a space and maybe just watch, I don't know, but, you know, giving people an idea of that, they're included no matter who they are, what they are, all shapes and sizes, you know, anything, we really just have to make this about, you know, the person and not about necessarily the disease or anything else that we bring bias wise to that.

And I think one of the other important things is when we talk about Parkinson's the mind and the body are so connected in this space. So I think, you know, we talk about motor symptoms and how people are going to do what their disease course. But I think if we don't think about how then the mind and the shame and all these things that, you know, we're talking about today affect that person each and every day for every minute of their day, for the six months, between when I'm measuring their tremor in my office, then I think we've really missed the boat. So I think we have ways with Parkinson's I and Greg believe to help people to thrive, you know, every day if they wake up and they try to, you know, do some exercise and find ways to connect socially, find ways to you know, find a tribe, find, you know, these different lifestyle choices I think, you know, can really help you with the disease. And you can make that choice. And I'd love to have drag, to spend a minute talking about sort of the concept of self agency, because I think when people feel in any culture, like they have some control of their outcome. I think that people can feel much better. And, and I don't think we've brought that up, you know in in this dialogue yet?

Gregory Pontone:

Yeah, no. Before I talk about self agency, I just want to echo some of the things that indu said that I think are really, the first thing is, is that this educational process is really two way, two

ways. You know I can tell you that my practice is informed by my interactions with patients. Maybe more than any other single factor, you know, more than the textbooks I read, my practice is informed by my patient's experience. You know, I learn all the tricks and then I pass them on, you know? And so I think, you know, if we can learn about cultures, we can then translate our interventions to better fit people in different cultures. You know, in weather, you know, that's the cultures we're familiar with that, the ones we're in familiar, what's an unfamiliar with. I think that's really important now, you know, in terms of self agency, this sort of gets back to this disease happens to you and there can be a sense of loss of control, right?

You know, I, how did this happen? Why did this happen? I can't do anything about it. And then you have to come back to, well, I'm still the captain of the ship and I can show up. And I think that's the best thing. And my favorite thing that Indu says is show up because so many times people say, I don't want to go to the support group because I'm afraid, I'll see somebody with severe symptoms and I'll be freaked out and it'll worry me, but you know what show up and become again, part of that community, you know, part of that shared experience. And that's what self agency is it's instead of being blown every time the wind blows one direction or the other, and, you know, being sort of a drift self agency is saying, I'm making a choice to show up. I'm making a choice to participate. I'm making a choice to engage. You know, I'm not denying the disease. I'm not hiding in a corner, ashamed or guilty. I'm doing the best I can. And for everyone, that's going to be a little different, right? It's going to be part of their individual choice. It's going to be part of what their culture values. And then, you know, hopefully as a community, whether it's through mentoring or buddies or support groups, we can help them find, you know, the best direction to, to navigate this experience.

Jenna Deidel:

Well, that's a really lovely piece of encouragement and call to action. And I think for everybody here to sort of wrap up this great conversation and you know, these, these these health disparities, you know, webinars in this series, unpacks tries to unpack really complex issues. And always we come to the end of the hour and often feel we can be left with more questions than answers. And that's okay. You know, this is, this is, we're all working on this together. But that idea of showing up, and I think, you know, while there is much complexity to this issue, I also noticed a really lovely exchange in the chat or someone asked about, you know, I feel more comfortable kind of using a walking stick, but it doesn't really, you know, I, I'm also running into my own vanity with that. What do I do?

And then a suggestion to say, paint it purple. You know, make it something you love is kind of what I, I interpret that suggestion to say, and I've met many friends who similarly, you know, their walking stick becomes a point of an icebreaker. It's a piece of art. It's a piece of conversation. It's a piece of your identity. It's, you know, you maybe have many and you get to choose from them. So I'm hearing, you know, while this is complex and can feel really heavy to

dig into, I think, to walk away with this idea of both show up those, that simple phrase you know, when you can, and also to, to make something worth showing up, to make it something that you love. And that means something to you, and that may not be, you know, the Parkinson's specific cycling class for you.

It might be your church choir and that's okay. It doesn't have to be backed by tons of Parkinson's research to make it matter for you and to help you live well. And I think when we really boil it down to an actionable, you know, sort of phrase, I think that's what I've taken away so much from getting to learn from both of you. And I hope that that's something that's helpful for folks that are listening today knowing that this is complex and Parkinson's is complex and it, and it's, you know, it's not, it's not that simple, but you know, as we, as we wrap up here, you know, the very top of our hour and we could definitely continue this conversation and we'd love to. So if you were on here listening to us and you have more questions, please do send them through.

I'm really happy to, to hear those. I think one of our, our background assistants can add my yeah, there's blog@dpf.org. Couldn't be easier. Send us your questions. We use those to create our blogs, to create a webinars, all of our good stuff and really want to thank your our two guests today, Greg and indu. Not only for your time today and your very busy schedules, but for your commitment to our community and to your commitment to this work. No doubt that voices like yours are helping us improve the lives of people with Parkinson's have all kinds of people living with Parkinson's. Also want to give a quick, thanks to our partner on this series, dance for PD who you know, support supports this work. And it's been a great conceiving partner of this health disparities webinars series, and a reminder to everybody here. If you missed anything, we covered a lot. You will get that recording. You will get a transcript if you prefer to read through and please do follow up with us when you have more questions. And I think we'll, we'll wrap up today with just a big, big moment of gratitude for everybody, including the participants and folks who chatted to us. So thanks everybody and live well. And we'll see you on the next.

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