Monitoring And Managing Parkinson's Symptoms Transcript

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Introduction and Dr. Mischleyu2019s Background

Hello, Dr. Mischley, thank you for joining us today. My name is Dr. Pickut and I'm the co-host for The Parkinson's Solutions Summit 2.0. Today we'll be speaking with Dr. Mischley on her work for people living with Parkinson's.

Laurie Mischley studied naturopathic medicine at Bastyr University, and holds a Master of Public Health in Epidemiology and a PhD in Nutritional Sciences from the University of Washington.

In addition, she holds appointments at both the universities. Her work is focused on identifying the nutritional requirements unique to individuals with Parkinson's, and is published on coenzyme Q10, lithium, Nad+, and glutathione deficiencies.

She's a principal investigator on the Modifiable Variables in Parkinsonism study, which is attempting to describe why some people with PD progressed slower than others.

She's also working on ways to study, package and deliver evidence based lifestyle modifications as a therapeutic strategy. She founded the Parkinson Center for Pragmatic Research and the Canine scent-based PD screening tool.

ParkCanine Dr. Mischley developed a patient reported outcome measure to assess PD severity and built the Parkinson's Symptom Tracking App, the PRO-PD APP.

And Dr. Mischley is instructor of the online series called Parkinson School. Dr. Mischley maintains a small clinical practice at Seattle Integrative Medicine focused on Nutrition and Neurological Health.

Health of patients with parkinsonism. So, Dr. Mischley I'm curious as about your work and the scope of it, and thank you for what you do for the people we serve with Parkinson's.

So this PRO-PD APP, what lessons have you learned after the release, and could you tell us some more about it?

PRO-PD App and Symptom Tracking

Yeah. Thank you for the invitation to be here. I'm excited to be a part of this really fabulous panel. the PRO-PD is a scale that we developed a decade ago to meet the needs of our online study.

And what it basically does is it asks the patient to describe their symptoms. It takes subjective symptoms and quantifies it into a numerical value that researchers and doctors can use to track progression over time.

for the last ten years, I've been using it in research. Some other folks and Swedish registry has been using it in research, but it hasn't been available to the public.

And what we have learned in the last ten years is it is shockingly accurate, especially in the first ten years after diagnosis, when you don't have a lot of motor symptoms on which to judge progression.

So subjective symptoms are actually more sensitive and accurate early in disease than the objective ones. And so, donor Don Johnson gave us some money last year to turn the scale into a free app.

It's available on iOS and Android. It is in English and Spanish. And so for the first time, all of a sudden, people with Parkinson's have a tracking tool that they can follow their symptoms.

And so I'll say the first thing that I'm learning is that the global disparities are huge. I mean, global medicine is here,

right? Between telemedicine and the online classes I teach.

And being able to track people's symptoms on the same scale universally. Globalization of health care is here. And that is super exciting. I think I really overestimated the computer literacy of the elderly population.

And and I don't say that I say that in terms of that is a need we need to fulfill. Elderly people who don't have access to computers and computer literacy are missing out on a whole bunch of things that younger Parkinson's generation has access to.

and I've learned that you can do a lot with a little bit of money. I mean, it did not take much money to create a new skill that people can use, and it gives them a tool that will allow them to track progression.

And so, it's really exciting to see that it's not a big bowl of some money in a big, expensive lab that necessarily makes a difference. But asking the question differently.

And that's exciting. Wonderful. Thank you. Thank you for that work. Yeah. The pre-digital, part of our population is something that we, need to work on.

and that's something certainly, that this deserves a separate conversation. Totally agree. Yeah. Thank you. I'm also curious, about, what you learned from your research with the modifiable variables in parkinsonism study and, in particular, attention to the people who are doing less well versus the people who are doing very well to excellent.

Can you help us understand that? Yeah. Yeah. Well, a little bit of interesting background is that the approach to research is called the positive deviance model.

It was born out of Tufts. Some nutrition researchers noticed that in a certain village, some kids didn't grow. And among a kid among a village of children that didn't grow, there were a few that actually grew quite well.

And so what they decided to do is study the population and find out what was different among the kids, because that didn't include the treat, the positive deviance that people do, the outliers doing unusually well as the cases in the others as the controls.

And it's a common sense question like what's different about the people doing well? But in 200 years of Parkinson's, nobody had applied to that question.

In that model, to Parkinson's, we complain about the heterogeneity, but no one had ever asked why. let's let's use the heterogeneity in the diversity to our advantage.

Right. So all this study is, is an internet based survey twice a year for the last 10 or 11 years. So we've been sending people a survey saying who are you?

How are you and what are you doing? And then on the back end, we write code to find out where the people doing unusually well.

Positive Deviance and the MVP Study

so I think, first of all, lessons learned are that you don't need double blind placebo controlled, expensive, multi-million dollar studies to get really good information.

Like you can just ask patients how they're doing, what they're doing. And that gives us reasonably good information. we have learned that this disease is so much more modifiable than we ever thought.

I mean, 7% of people are not getting worse over time, according to the preliminary data. we don't two important words the positive deviance and pragmatic.

So explanatory research at the end of the study tells us a little bit more about mechanism of action. Pragmatic research tells us at the end of the study what can people go do?

Right. And so we we're all pragmatic. We're all pragmatic. And so we can't tell you why anything works. But we have the cheat sheet that tells you the people who are progressing.

We know what they're doing. We know their credit score. We know how many friends they have. We know what foods they eat. We know how much they exercise.

We know what type of exercise they do. We know they use some stress management techniques. And so it's pretty clear to have that coming into focus. Right. And so all we've done so far is a cross-sectional survey.

I don't have the statistical skill set to follow people over time. IT control for all those variables. And the study has been grossly underfunded. So we've just been collecting the data and we can take slices of it and look steps now will be to hire a statistician who can do it for real and and tell us if you go from eating cheeseburgers and milkshakes to, to broccoli and salmon, does it change the trajectory of progression?

So we have the data now to answer that question. We're in the process of doing that. Wonderful. Oh, I'm hanging there waiting for your for your analysis.

That will be very, very important. I agree lifestyle is is important for everyone and particularly if we have, this neurodegenerative, I don't like to use the word disease, so I'm searching, syndrome.

Syndrome. Yes. Yeah. Particularly important for people, for everyone, and also for those with Parkinson's and parkinsonism. So do you do you filter out, do you take the diagnosis that people report?

do we know how many of those people have parkinsonism like vascular as opposed to idiopathic? Sure. So we we asked that question of everybody and we ask it every six months.

Because obviously a lot of people who start as having oh, this looks like idiopathic Parkinson's will later be diagnosed with something else. Yes. And so yes, we have collected and like as the diagnosis changes, but again we can argue for like what is the difference if it's Parkinson's or MSA.

Like how does it change our treatment? How does it change our approach? What does that actually mean to the patient? I mean, I don't I suppose, you know.

You're right. And this data that you've collected should be rich to help us parse that out. That's wonderful. Thank you. Thank you. And we need more people with PSP and MSC and Lewy Body dementia.

And so for those really like please for the people listening who have different forms of parkinsonism, you are invited to join that study in the MVP study okay.

Super start. So thank you. Learned a lot so far. And I appreciate, you instructing us all, if I may ask, what work are you most excited about now? well, the one I'm honest.

The thing I'm most excited about is taking all of the data that the Swedish group and I have been collecting over the last ten years using the Pro PD, collect all that Pro PD data, put it into a repository, because we now have ten years worth of accumulated longitudinal data on what makes symptoms better and worse.

So if we can put that into a big repository, I think we're up to like 50 or 60,000 people. Who like a big file. Like a big, huge file take to identify it and hand it over to AI and machine learning.

We are going I mean, it's an entirely different perspective, using an entirely different outcome measure now more sensitive early in disease, asking the questions from entirely different perspectives, but with a tool that we could not have conceived of a decade ago.

And so right now, even though AIML is available and people are having a heyday with it, and it's causing quantum leaps that our understanding, the limitation we're having and applying it to neurodegeneration as the data sets that we're applying it to stink there late stage downstream consequences of something that started decades earlier.

AI, Redefining Parkinsonu2019s, and Modifiable Syndrome

So even though we have this great tool, we don't have a, a data set that we can go play with it. And to understand. Yeah. Right. And so yeah. So I'm betting on that data set.

okay. So yeah. So you're working on that. That's wonderful. So and the people who participate of course in a survey, they are anonymous. Yeah. Completely anonymous. Completely. Yep.

Yeah. so, so you know, with that with, you know, building that repository and handing it over to AI, machine learning is is one thing I'm super excited about.

and with that then comes this redefinition of Parkinson's. Right. Because truly, for a couple hundred years, we have defined this disease by what the doctor can see. Yeah.

Right. And and so it's kind of paradigm shifting to all of a sudden start talking about Parkinson's as an entity, as defined by what the patient experiences, the apathy, the fatigue, the sleep problems, the erection problems.

And so all of a sudden, like we're talking about redefining Parkinson's from the patient centered perspective. And this is also leading to a redefinition of Parkinson's, even as a neurologic disease.

Like, I really think it is a metabolic disease with neurological consequences. Right. And so I think all of these looking at it differently, asking the questions differently, is, is not just about finding should I eat more spinach or carrots?

Right. But it is really like wow, when we just like start all over and look at this from a new perspective, what what do we see? And so that's that's exciting to think of this as a I think in the next couple years, we are going to be talking about Parkinson's fairly routinely as a modifiable syndrome, more like type two diabetes.

I think it's here. It's coming. Wonderful. Extremely interesting. So in the in that light. So we're going to be like lifting the curtain or opening the curtain on a number of variables that we can maybe actionable items, attainable things.

So, what can we do now or what what is your sense that the things that are actionable, things people can do that would have a meaningful impact on their lives?

Well, there's the obvious stuff like diet and exercise, right? Like every single person should exercise every single day for at least 30 minutes. Right.

And to the extent that you can, it should be physically intense cognitively challenging outside your comfort zone, and so difficult that you're making mistakes and getting frustrated.

Okay. And what about measures. measures of physical activity or measures? metabolic. Oh, I think the other. Yeah. Lab tests, I mean, so eat your vegetables and do your exercise.

It's like the baseline. Everyone should. I don't care what disease you have or what label we put on there. Right? From a Parkinson's perspective, the simple, simple things that everyone can do. Our a couple lab tests, right. Like homocysteine levels.

We have three decades of data that says the leave a dopa we give you raises your homocysteine. The higher your homocysteine and the greater your likelihood of dementia.

And all you need to do to take have your cake and eat it too, is to take a little B vitamin with your liver dopa and you

can reduce the homocysteine, hopefully preventing dementia.

Right? Like it's a $20 test once a year. Just have the doctor who is prescribing leave a dopa should be checking homocysteine levels once a year. We are inducing B vitamin deficiency.

It is our duty to monitor it and prevent the side effects from that. so things like, homocysteine and high sensitivity CRP is probably the other one. It's a $12 test, I think.

I mean, it is cheap. It is easy. There is data that says that people who are 0.8 or higher, notably more likely to not be alive ten years from now than people who are below 0.8.

Like, if you're not inflamed, then stay the course. Good job. But if you are walking around with low level chronic inflammation, figure it out. Change your diet, figure out what's causing it, and make it go away.

So I think there are labs. Labs are where we are going to see real big advances in the next couple of years.

Actionable Labs, Diet, and Practical Tips

The low hanging fruit, affordable, available, modifiable. And we're just not using them. And people can ask their provider quizzes, a routine lab tests.

I consider them routine lab tests. Yeah. I mean, they're available, routinely available. if. Requested by a provider. Right. Isn't. Yeah. Yeah. Okay. All right.

Well, that's a very good tip for people. So if you have a few more minutes for us, I have a last, last question for you. and I think you've, you've, alluded to diet a few times.

So I'm curious, what tips do you have for people living with Parkinson's struggling to change their diet? so I know that the right answer is supposed to be baby steps, right?

Slow, steady. Get informed, learn about your options like slow and steady is less stressful and gives you more time to acclimate. But the problem with that is you don't really get the benefits right.

You continue to feel kind of book for the next couple of years until you figure it all out and you never get that feedback that diet is or is not making a difference.

When I give patients, option in clinic and I say, just pick two straight months where you don't eat anything on the avoid lists and anything on and drown yourself and stuff on the good list.

I really do think people get better results. that's not possible for everybody. It's not feasible for everyone, but it is so rewarding to have people come back two months later and just give me a list of 27 things that have gotten better, you know better.

My meds are working better, my fatigue is better, my brain fog gets better. My, you know, like like it's like, I don't need to tell. They're not two months in.

They're no longer changing their diet or eating their foods. I'm asking because Laurie said to they're doing it because they feel so much better when they do.

And so, I think if you can spend a little bit of time doing some prep work and kind of figuring out what will I have for breakfast, what will I use for snacks, what kind of lunches?

When I'm on this two month period, what kind of lunches will I eat and go into it? Making a plan? But I think my experiences, if you can kind of carve out two months where you make a commitment to self, to just let the pendulum swing the other direction and ask, what would it feel like if I did x, Y, and Z?

And then, you know, there are a couple different diets being studied the ketogenic diet, the mind diet, the Mediterranean diet. Our diet is called the pro diet patient because it's based on patient reported outcomes.

And so all of them have a couple things in common fresh vegetables fresh fruit, nuts and seeds, beans, non fried fish and olive oil. everyone right. Like if we can just start there, like every single person on this call can find some way to increase some of the things on that list easily, you know.

Oh I can start having some more locks for breakfast. Okay. I can put in a little extra spinach in a morning smoothie. I can put some extra olive oil on my broccolini tonight at dinner.

I mean, so so if people can just I think it's a lot easier. People tend to prioritize giving up the bad and and it ends up being about deprivation and restraint.

And and if you just ignore the bad and just focus on like, how many servings of good stuff can I get in my body today possibly, you know, and that I think that makes everything easier.

And you start feeling better faster. Okay. Thank you. That very, very important tips. And I'm sure people can learn more about, this topic at the Parkinson School.

Oh yeah. Yeah, yeah. So everything I know is in an online program called Online Parkinson's School. And I'll make a pass that you all can use. Okay. So really, we'd appreciate that.

I'm sure our viewers have been enriched by your knowledge, and I'd like to thank you again, for being a guest on DrTalks Parkinson's Solution Summit 2.0.

Thanks for the invitation. Thank you.