Introduction and Speaker Background

Hello and welcome to the Parkinson's Solutions Summit 2.0. I'm your co-host, Dr. Barbara Pickut. It's an honor and a pleasure to introduce a colleague of mine, Dr. Reversa Joseph, with whom I had the great opportunity to collaborate on the first ever textbook for integrative neurology back in the day with editors McBurney and Roy.

We wrote a chapter on Parkinson's and integrative medicine together with Dr. Laurie Mischley So it's wonderful to be here again. Dr. Joseph, I offered to introduce you, so I will do that now.

Okay. Thank you. Dr. Reversa Joseph is a board certified neurologist specializing in movement disorders and inter operative monitoring, with a profound focus on treating patients with Parkinson's disease.

She employs a comprehensive and integrative approach. Dr. Joseph obtained her bachelor's at Columbia, followed by her medical degree at Georgetown. She completed her neurology residency at Yale and pursued a fellowship, training and movement disorders with a focus on deep brain stimulation and botulinum toxin therapy.

At Georgetown. Additionally, Dr. Joseph completed a fellowship in clinical neurophysiology at the National Institutes of Health, where she specialized in intraoperative monitoring and autonomic dysfunction in neurodegenerative disorders.

Currently, she serves as a director of the Movement Disorders Clinic at the Chalmers P Wylie, VA. Doctor Joseph initiated a Parkinson's multidisciplinary team at the VA to enhance the care provided to our veterans with Parkinson's, utilizing a whole health approach.

She integrates various modalities to offer comprehensive peer care for patients with neurodegenerative disease, and strives to eliminate health disparities in the care of patients with Parkinson's.

Reflecting her passion for ensuring that all individuals receive equitable access and quality care. So it's, it's an honor and a pleasure to to, have you speak with us today.

And, thank you for your time to do this. Could you help us understand the historical background? the age of exclusion and promoting inclusivity in Parkinson's disease.

Why Diversity Matters in Parkinson's Research

So, historically, how have African-Americans been excluded from research? And why is inclusivity in research important? well, so thank you again for having me.

it's an honor to to, to be on this, journey kind of with you, over the years and so very excited to be able to reconnect and in this capacity, I would say that one of the key issues kind of contributing to just, the disparity that we see in Parkinson's disease treatment and patients are that are African-Americans and also and research is kind of this historical lack of diversity and clinical research, that, African-Americans have really not been participating.

you know, and I think a lot of reasons for that in terms of like, clinical trial participants, participation predominantly enrolled participants from Caucasian backgrounds.

and I think that that there's been a historical kind of mistrust of the African American community that has led to that. But I think just even ongoing, there's just, a lack of awareness in the African American community and also just lack of engagement in the African community to participate in these clinical trials.

And so I think it's kind of a multifactorial approach of what's kind of leading to that. Definitely there's there historical

medical mistrust that's rooted in things as well, which we've all heard, or things like of the Tuskegee, syphilis trials.

and just, just other trials, you know, along the way. but I think that that has definitely led African Americans. the community in itself to just kind of feel a mistrust for the medical system overall.

And although there's been lots of things in place these days to try to help prevent those things, I think there's still really a lack of awareness about the importance of clinical trials.

and so because of that, then there's also a lack of engagement of African Americans, like, we're recruiting African-Americans into research that further leads to that disparity.

Understood. Yeah. So when we look at Parkinson's specifically or thinking about clinical trials in Parkinson's, why would, we be interested in, all being open and, and, having the representation of, more diverse populations in that.

Right? Well, so I think, you know, if we look back, we think that just understanding Parkinson's disease, it's, you know, it's a complex neurodegenerative disorder.

patients present kind of, you know, a wide range of symptoms. that's a variable kind of disease progression. So we, we understand that it's not kind of a one, kind of fit, all kind of disease.

You know, we see it presenting in different ways, although there's characteristic symptoms, but patients may manifest in progress, at variable rates. And so I think that most of the clinical trials that, you know, in terms of what we see in terms of treatment, clinical trials for treatment and drugs have really only been studied in basically the majority of Caucasian, people of Caucasian background.

And so I think if we're trying to really generalize these studies and to, you know, other segments of the population, you know, do we really know that these the findings are generalizable to other populations if we're really not studying them?

and so I think, I think it's really important that we are sure that the treatment response, you know, even just gender, you know, to other gender differences in treatment responses.

And we we do we do know that, you know, in terms of certain medications, we have to adjust, the dose based on weight and things of that sort. And so that gender may play a role because, you know, women may not have the same weight as men.

And so things of that sort. So we already kind of know that there's certain treatment things that we have to adjust even based on gender. But I don't think that we're really ever looking at that based on race.

and so are there differences? You know, we really don't know because we're always thinking one segment of the population and only, you know, really, looking at these trials and one segment of the population.

So I think, I think that's, that's one thing. And then, you know, if we're trying to really look at addressing health care, health disparities, we see that African-Americans are diagnosed, misdiagnosed and diagnosed later in the course of the disease.

So, you know, are we are we missing, you know, are we missing things in terms of, you know, what what we could do in terms of treatment, in terms of, delaying, you know, disease progression?

Well, we don't know in African-Americans. We're not we're not reaching them until later in the course of the disease. So, you know, that I think that addressing that health disparities piece is one increasing awareness about, Parkinson's disease.

It's not just a white man's disease. women are affected. it affects all races, you know, so kind of trying to change, the narrative of what we think and we see and what we've learned, even just in the medical profession.

You know, if we look at textbooks, when I was, in medical school, you saw old white men hunched over. And that was the picture. Parkinson's disease, you know, so, you know, if I'm treating someone in the clinic coming in, if that's what it's in my mind, and, you know, we, you know, how have things.

If that's what's in my mind, as an old white man. And I'm not thinking of that when, you know, an African-American woman comes to my office, or to someone else's office, you're not thinking of that, that they could potentially have that.

So I think, I kind of got off onto that. Another tangent about, about that, but just kind of changing the face of, of what we consider as Parkinson's disease.

So that's kind of one of the big things that I'm really trying to advocate for, as well as increasing participation of African-Americans in clinical trials.

Yes, indeed. Yeah.

Misdiagnosis, Awareness, and Community Education

The, the, the, age to, which we, we have a preconceived, age of 65 and, and, and older. Right. And we know that. Right? That's not the case. The case and not all people with Parkinson's present with a tremor, for example.

Exactly, exactly, exactly. Right. And so, you know, and I think a lot of the things we want to and we're talking about like risk factors, so are kind of like prodromal symptoms.

You know, some of the things we know about REM sleep behavior disorder, you know, loss of sense of smell, these types of things. you know, we're thinking about maybe some of these things could be potentially risk factors.

And if you add many of those up, you know, that can maybe increase one's risk of developing Parkinson's disease later on. But again, even those things were all studied, you know, and Caucasian white men.

And so, you know, are there different risk factors or prodromal symptoms that are in the African-American community? We don't know, because we haven't studied this to know that. So, you know, I think that that, that, that all of that is really important to to have a wide range of understanding how the disease affects all races.

I, I strongly agree with you. Yes. Epidemiology that we base our studies on, is skewed. Right. Because. Yeah. Yes. And that's very important for research.

there was, for example, the data that, some epidemiological studies had shown that Parkinson's was less prevalent among the African-American population.

But if my understanding is correct, that's being looked at, and that might not be the case, right? Absolutely. But I mean, so that's that's one of the factors, you know, is that we don't have a lot of, trials that, you know, one that high participation of African-Americans that we're looking at.

But even if, you know, you're looking at the rate of diagnosis, you know, I think that what's what's happening is that we're missing a lot of people. And then again, catching them later and then later, later in the course of the disease, they actually have worse disability and actually are kind of dying, you know, so we're just we're missing a lot of people, I think because we're not we're not catching them earlier on in the course of the disease because of just misdiagnosis and just the lack of awareness, even within the African American community, you know, so that's a lot of the efforts have been doing is trying to just education this, you know, increase you just raising awareness about Parkinson's disease.

Often the times I'll go, you know, to a church or community center. And I ask, you know, has anyone ever heard of Parkinson's disease? And they never heard of it.

But then when I say, oh, you know, have you seen someone shaking, you know, tremor or oh, the shakes so that, you know, they, they understand it by different terminology, you know, the shakes or something like that.

Oh yeah. My uncle had the shakes or grandpa had the shakes. And, you know, we just thought he just had the shakes. Well, that maybe a little bit more than just the shakes, you know?

So we have to, you know, grandpa never went to go seek treatment about it or his primary care. They said, oh, that's old age. Everyone gets a little tremor and, you know, don't worry about it kind of thing.

But we need to move away from that. And actually, you know, have patients be be, you know, evaluated for this. And, and I think a lot of part of that too, is that patients don't get to see specialists like, like you and I, I mean rarely maybe they might see a neurologist, but most of them are not seeing movement as a neurologist.

They're not seeing, you know, the, the, the specialist, the subspecialists. So that also leads to that kind of misdiagnosis and lack of care and treatment.

Okay. And you're so can you tell us a little bit more about your work, your outreach that you've done and that you're doing and, and how we can all participate?

Right. We also, always can participate by, you know, where, you know, in your settings, in your social settings and, you know, at the community outreach that you do, just kind of spreading their awareness about Parkinson's disease in general, that it affects, you know, all people of all races, gender.

so that's that's one thing really kind of changing the narrative of what we are idea of, of who gets Parkinson disease. and so a lot of the work that I've been doing also has been with the Parkinson's Foundation, and we created kind of a novel learning institute to help, increase, research advocacy amongst patients with Parkinson's disease that are African Americans and their caregivers.

So, we held our first inaugural one, at Morehouse University, our Morehouse College in, and Atlanta. And so we partnered with Morehouse, as well as we had, developing this, this learning institute was, took over two years, but consisted of, patients with Parkinson's disease that were African American, their caregivers, social workers that were African American, nurse practitioners, movement disorder neurologist and other members of the Parkinson's Foundation team.

and we met to kind of really go through all of the, the sessions and the presentations to make sure that they were culturally competent, you know, like culturally sensitive, that the pictures and the photos and the presentations were representative of African Americans, and that the content really reflected the population that we were seeing and also made sure that it was, you know, not to too technical that they couldn't understand.

So, the really did a good job with that. So, you know, went through many checks. So after I, you know, did a check and then, you know, we'd have a patient with Parkinson's disease go through and say, oh, well, actually this is, this is very, you know, offensive to me.

Building a Research Advocacy Learning Institute

So sometimes some of the language of how we see things can be and, you know, that might be something that as us as a neurologist or other health care professionals, we don't, we don't even recognize.

So I think that was really important to have that collaborative team approach and including patients with Parkinson's disease. And that process was really helpful.

So we had that learning institute. We had over like 40, participants. come to that, it was over four days and we taught them about, research, clinical trials, all of that, you know, from phase one, you know, all the all the different phases of clinical trials of what's involved, how what oversight is involved.

IRB we process all of that. And we even went into, you know, talking about the historical, issues that have have happened. You talked about the Tuskegee, you know, the syphilis study and and others, Henrietta Lacks, all of these things, we really delve deep, even into those things and, try to get their opinion about it, understanding about it, because, you know, it's nothing to I think if we just overlook those things and don't discuss it, I think that that also leads to the mistrust.

So we wanted them to know, hey, we understand that this is out there. We understand that this may be a fear, but this happened. And now all of these things are in place so they don't happen again.

And so I think that was a that was a really good session that everyone seemed to really, really appreciate. and then a lot of part of it too, we had a lot of time for a roundtable discussion and really getting their opinions and things.

And so basically, with completing the program, participants then were trained and equipped to be able to go back into their community, one, to really raise awareness about Parkinson's.

So many of them had not even told family members that they had Parkinson's disease. And so I think trying to even just change that paradigm, that it's something you have to do in silence or keep in silence and not talk about.

I think just overall in the Parkinson's community, not just African American community, but just overall, you know, just having patients feel, you know, okay, to to share their story, to share their journey.

I think that what makes it so powerful and so I think that they were really empowered to feel comfortable to share their story because they understood that by doing that, that helped to really raise their awareness.

And, you know, to help us really push forward and, you know, through their understanding and education that others can then maybe if they're having similar symptoms, that they will go and seek treatment or, you know, seek, seek care to maybe get a potential diagnosis, if that's what they have or something else.

So I think that really empowered patients, to really share their stories and be advocates for that, and then also to just empowering them about the steps of their process to get involved in research.

And what one thing I thought was very interesting. So many are several of them were seeing movement disorder neurologist and were being treated at like tertiary centers or academic centers, but they had never been approached about participating in clinical trials.

And these were at universities that actually had trials going on, but they had never been approached about participating in clinical trials. So I think that institute also tried to help them to have self-advocacy.

So, you know, giving them questions about, oh, I do you have clinical trials? What type of clinical trials would I be? You know, eligible for any clinical trials.

So really giving them kind of the tools and the questions to ask because sometimes you don't if you're not asked the question to, then in return, you may not even know the questions to ask about it.

So yes, giving people the vocabulary and the voice, that's marvelous. That's wonderful. Yeah. Well, thank you for that. how will how will the Institute move forward?

Are there national plans or how can people find out about this? right. Well, so, so I, I did present this at the American Academy of Neurology. and then, we're following up with that.

So second, a second phase of that has been, now, kind of monitoring what the research advocates are now doing in their community. And so, so they've had kind of, they came from various places throughout the country.

So, and we kind of selected sites where they had, you know, higher rates of African American population. So like Atlanta was, you know, a site and then Washington DC, there was North Carolina, there was Chicago.

So in those various sites, those research advocates have gone back and now have put on various events. And so now we're kind of tracking the things that they're doing.

and so that will kind of be our second kind of presentation of that, you know, how how active have I been in the community since that learning institute?

And then the plan is to right, you know, to have a paper about it to then because this is really could be a model not just for Parkinson's disease states, but for other diseases states in terms of, you know, teaching, you know, education and you know, how to become advocates, you know, develop research advocates and patients, participating in research so that that would be the next the next phase. Yes.

And the thing that kudos, kudos to all involved. That's very important work. Yes. I'm curious about your firsthand experiences, with working in the clinic.

And have you had any or witnessed any, challenges or specific successes that, in that have been in your hands? Yeah. So, you know, I would say, levels of challenges and, you know, and also successes, but, one thing that I did notice that I felt that care was very fragmented, now fragmented now I work, at the Columbus, VA, and a little different from, you know, those that may kind of just be in the private sector.

I think that the veterans, have access to a lot of things that maybe those in the general population do not, but even still, the care seem to be very fragmented for them.

you know, maybe you put in an order for something, you know, to see the speech therapist, but, you know, maybe it doesn't get done for a while or, you know, just different things like that.

So I wanted to bring all the care teams together and even just even like the primary, I just feel like no one was talking with each other. And so what I would see the patient, they would always come with me with all the other issues that were going on, and this things just didn't seem to be getting done.

So I kind of became like the fixer. So after that, my visits, we were doing a lot more than just, you know, you know, medication management. But it was really a lot of other things that were affecting them that weren't being addressed.

And even social needs to not just weren't being addressed. So, you know, I developed this multidisciplinary team approach where we basically had team meetings, with, you know, the primary care doctor, the social worker on the team.

We have, psychologist, we have the speech therapist, the occupational therapist, the nutritionist.

Multidisciplinary Care and Supporting Caregivers

And then we have this whole health program through the VA. So where in that program really focuses on helping the patient to identify why their health is important to them.

You know, I think a lot of times as physicians, we just assume, you know, well, the patient we just want you to be healthy. We're going to do all these things to make you healthy.

But are we really addressing like what's important to them about their health? So, you know, for instance, if they, you know, want to improve their strength so that they can be able to pick up their granddaughter, then I need to be tailoring their approach to helping them to do that, versus all the other things I might think is important to them.

Those things may not be important to them. So we're really trying to address what's most important to them about their health. So we have someone from the whole the whole health team on the on the team as well.

So then we're able to know basically all my patient cases, we discuss. And so oftentimes it's actually really helpful

for me to because when they've seen the speech therapist, they've told the speech therapist things that I didn't know.

And the speech therapist like, oh, well, can you place this order for this? Because I think this could be really helpful for the patient because they told me that they needed blah, blah, blah, blah.

And I was like, oh, wow, I had a half hour visit and they never told me that. So I think, you know, and that and that's that's the beauty of it. Right?

Because other providers see them in different lights, and maybe they're both free to share something with another provider. Maybe they forgot to tell you. So, that so that collaboration in the care, I think has been very, successful.

and I think the other the other aspect of what I've felt has been a challenge is really, I think there's been a lack of, just addressing the needs of the caregiver or their care partner.

And I think what's been really good in the VA is that we have a whole, caregiver support system, where they this team is only for the caregiver. They don't do anything with the patient.

It's only for the caregiver. So, you know, I can refer a patient to that program. and they, you know, have support groups for them. They can get them counseling if needed.

They can get some respite care. They can get yoga, massage therapy, all these things just for them. So I think that's been a really good thing to add into the care approach for Parkinson's patients, because it affects the whole family, not just the patients. So, I think that's been a good success as well.

That's great. It's so patient centric with all these touch points that you have for people that are looking at all the different facets of the whole human being.

Right. That's that's wonderful. so you've talked a little bit about caregivers. do, can can you tell me in, in terms of the inclusivity and, and, perhaps our not seeing our implicit bias at not seeing them do you have any thing more to add about, caregiver, care?

Yeah. So, I mean, I think yeah, I think so. I think that's often something that we, we don't talk a lot about. and I think at least what I was kind of more not in the VA system.

So outside of the VA system, there really wasn't any discussion or thought about. The caregiver honestly, is just, you know, the patient comes out and it's just everything about the patient, you know?

And I don't think there was one time where we were trying to address something that was going on with the caregiver, or even asking the caregiver any specific things going on with them.

And so, you know, we we have to really understand that, you know, oftentimes, you know, it's the caregiver helping our care partner, bringing in the patient.

you know, at times and oftentimes they're the ones helping to remind them to take their medications, administering their medications, you know, helping assisting them with transfers if they're at that point.

So there's different stages that patients have with Parkinson's disease. But even all along those stages, I think the caregiver is also affected. I mean, it's a it's a mental, and physical kind of, impact on them as well as psychological impact on them.

you know, some, you know, when I've had now that I've had the chance to be able to address some of those needs, you know, some of them, you know, feel a lot of guilt, that the fact that, you know, they, they had this vision of what their life was going to be and retirement and, you know, they felt like, wow, they have this diagnosis of Parkinson's disease and that, you know, their care partner has this diagnosis and now their life is completely up.

You know, it's never going to be the same. And so really just letting them know that, you know, that's why I'm here. And others are here to help support you both in this journey and that we can try to help that what you envisioned.

It may be a little different, but you're still going to be able we still want you to be able to do those things that you really wanted to do. So that's that's our goal.

And this whole, you know, process is to help that journey. You know, maybe there might be a little deviation from what you truly envision, but we can still help you to achieve some of those things so that you can still enjoy the life that you want.

So that's wonderful. That's such, such worthwhile work. We we've been offering, mindfulness and compassion training for caregivers separately in a separate group.

And there's, that seems to be a lot of, a lot of healing, in those groups. so absolutely, absolutely. I guess, and I think that the, the key part of that is separate.

I think that that, that there needs to be a recognition that there does need to be some, some really support just to the caregiver, you know. So, yes.

And you also offer respite care, you mentioned and you have a psychologist. Yeah. Right. And we have a psychologist. Right. And that can be utilized by a caregiver.

You know, because a lot of that now that the patient has access to all of that, but oftentimes the caregiver just not. So yes. And the system we do have, they have access to that as well.

Okay. Wonderful. Can people contact the Parkinson Foundation or go on their website to find out what's absolutely absolutely. So Parkinson's Foundation not org you know, there's a whole lot of resources, that they provide, like educational resources they can send to you.

you know, one of one of the big pushes that they do have is about when you go into the hospital, they have this aware and care kit that you can take with you that, has information about, you know, saying that you have Parkinson's disease, saying that you have medications that need to be given at a certain time, certain medications that you should not be given because you have Parkinson's disease.

So I think it's a really good, kit to have to, you know, to take to the hospital because a lot of times, our Parkinson's patients, you know, don't do so well when they're in the hospital just because there's a lack of awareness of the care team about what's needed in terms of that, that they need to get their medications on time, that they shouldn't be given certain medications and things of that sort. So, I think that helps just increase their awareness.

And, and the hospital, which is unfortunate, but we still need education there too. We certainly do. We certainly are. Has Parkinson's Foundation dawg.

People can Parkinson's. Foundation that I guess. Okay. And how can people find you. Yeah. So, basically if you Google googled my name, I'm just for those of you guys that I'm at the Columbus VA.

Okay. Yes, yes, yes. We well, I thank you so much for your time. I think that this is so rich, in terms of, the things that you've, shed light on for us all.

And, I want to thank you for your work, as always. And it's been my pleasure to, to be with you today. Thank you. Thank you so much. Yes. That's good.

My pleasure as well. So.