



Care Partner Research and Training

An Interview with Dr. Jori Fleisher

Davis Phinney Foundation

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

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

Hello and welcome everybody. My name is Melani Dizon. I'm the Director of Education and content at the Davis Phinney Foundation, and I am here today with Jori Fleischer. How are you doing?

Jori Fleisher, MD, MSCE, FAAN (Leslie Nan Burridge Endowed Faculty Scholar in Parkinson's Disease Research, Associate Professor of Neurological Sciences at Rush University Medical Center):

I'm doing great. Thanks so much for having me.

Melani Dizon:

Good. I'm so glad that you're here. We are talking today about care partners and Dr. Fleischer has done a lot of work in this space in terms of finding people who are underserved care partners who need support care partners who need more education about Parkinson's and Lewy body dementia, and how to help their person who's impacted. And we're really excited to get some of this, some of the work that you've done out in the field, and to inform our community so that we can take that information and help them become better care partners. So really appreciate it. Can you tell everybody a little bit about yourself before we get started?

Jori Fleisher:

Absolutely. So, I'm a movement disorders neurologist and an epidemiologist by training. And was introduced to people with Parkinson's as an undergraduate in college. And kind of never looked back. I knew that neurology would be fascinating and had been exposed to a lot of neurology in my own family. And so, kind of had brain disorders on the radar from being a young child, but once I kind of entered the Parkinson's community and got to know people living with this disorder, I just kind of haven't looked back since. So, it's such a wonderful opportunity to be here with you, and huge thanks to Melani and to the Davis Phinney Foundation.

Melani Dizon:

Oh, thank you. Thank you so much. All right. So, let's, let's talk about it. Let's talk about the power of human connection.

Jori Fleisher:

So, what I wanted to do is give you a little bit of background into sort of the work that my team has done so far and hopefully where we're going and how we actually, like where the rubber meets the road. How do we actually put some of these, you know, scientific findings into practice on a daily basis? So, here's what we know. We know that social isolation and loneliness are huge risk factors for adverse outcomes in older adults globally. And I think this has come to the forefront so much during the Covid-19 pandemic. But this was actually a problem long before Covid, and there is increasing study and recognition of the association between social isolation and loneliness with poor health co outcomes, poor physical outcomes, and poor mental health outcomes among older adults. And when I say social isolation, that's defined as a lack of integration of individuals in their social environment.

So, someone could live in a busy, you know, apartment or condominium complex surrounded by people and yet be socially isolated because they don't have a sort of daily connection with a network of people. And so, this has really risen to the forefront. Again, even pre-pandemic, there are ministers of loneliness. So, the United Kingdom created a position called the Minister of Loneliness, whose job is for the, you know, for an entire, for the United Kingdom to try to come up with a strategy to better integrate people. So, their strategy was to set out a powerful vision to raise awareness of loneliness and help people build connections to lead happier and healthier lives. There's a loneliness minister in Japan. They have met and synergized to talk about strategies across their different countries. And I want to point out this article written by a good friend, colleague, Dr. Subramanian, who studied the synergy of pandemics, meaning the social isolation that was going on for people living with Parkinson's, even before the pandemic, and then what that would mean in the future. And so, she really points out, and this is something that we hear about clinically, I hear in my clinic, day in and day out, was at the very onset of the pandemic during the lockdown. I talked with a lot of families over the video, and I would say, how are you holding up? And what I heard heartbreakingly often was, this is not all that different from our normal lives. You know, we couldn't necessarily connect with people as much as we wanted to because of x, y, and z limitations. Or we felt like, you know, we needed to kind of stay closer to home. And so, I think there's been a lot more attention to this in Parkinson's before, during, and hopefully after the pandemic.

And one of the reasons why sometimes people with Parkinson's and care partners for people with Parkinson's can become socially isolated is the disease itself. And as much as I'm a movement disorder specialist, I went into this field that is labeled movement. We know that so much of Parkinson's is not just the movement, the movement is the tip of the iceberg and the non-motor symptoms. So, things like constipation, acting out dreams during sleep, depression, and anxiety, all of these things can precede the onset of motor symptoms by years, if not

decades. And over time, even if there's a tremor or slowness or stiffness, it may be many of those other symptoms that really impact the quality of life. And as time goes on, as people age, as the disease progresses, we can see sort of increased number and severity of all of these different symptoms. And the way that they layer and play on top of each other can be really limiting for so many families.

And this is just a sticking point for me, which is people will often ask, you know, what stage am I at? And we have a staging system, at least in Parkinson's, and it's called this home in your staging system. And unfortunately, it only talks about the motor symptoms. So, it only cares and stages you based on our symptoms on one side. If so, you're stage one, both sides and mild, you're stage two, are you starting to have trouble with your balance, but you can walk independently, you're stage three, can you walk, but you need an assistive device like a cane or a walker? Well, then you're stage four and if you're dependent on a wheelchair or if you're confined to bed, then you're stage five. And where, where, you know, if someone says, what's my stage and what does that mean? Is that advanced? That's a great question. And unfortunately, a lot of the work that's been done, if you read a scientific paper that talks about, you know, x, y, z clinical trial of this drug in advanced Parkinson's disease, most people in those trials are stage three.

Melani Dizon:

Okay. Yeah, that's a really interesting piece. I feel like this is a really important piece for the community because we get the question all the time.

Jori Fleisher:

Yeah. And I feel like this is the soapbox that I'll probably, you know, stand on forever, right? If we're calling stage three advanced, what are we calling stage four in stage five?

Melani Dizon:

Right?

Jori Fleisher:

The answer for so long has been, we haven't been calling them anything. Mm. Because we haven't been paying attention. And it is not, I want to make sure this is abundantly clear. It is not that there is some magical cliff that you hit stage three and then people are just gone. That is not what happens. Mm. The literature would make us think that that is what happens, but it is incorrect. It just becomes more difficult for people to access the care that they need. And if those barriers are high enough and it's too difficult, let alone, then you throw in a pandemic, right? Then we lose people to care. We lose people to the healthcare system long before we ever lose them to Parkinson's and

Melani Dizon:

Right. So, if, let's say the stage three they're calling it advanced. Is it, is it because that's, we can't go, we can't help anything beyond?

Jori Fleisher:

That? No, absolutely not. And hopefully, I'll convince people that there is always something that we can do. There is always, always some, you know, somewhere that we can tweak. And I wish I could say, you know, yep. We can turn things around and we can, you know, cure this disease. Not yet, but hopefully there's, you know, so many researchers and so many labs, there's so much work going on to try to slow down, you know, and stop this disease and understand exactly what's going on in so many different flavors of Parkinson's.

Melani Dizon:

Yeah. I mean, I feel like I know, you know, plenty of people that were wheelchair bound and they didn't, they wanted no part of life anymore. They were so bad they couldn't move. They were in a wheelchair, somebody was pushing them around and they did something that changed that, and now they're walking around fine. Right. So, it's also not one of those things where there's no movement within these, you know, five absolutely coming to our stages.

Jori Fleisher:

Right? Yeah. I've had people who've come to me and, you know, have heard all kinds of myths and misconceptions about the medications. And so may have had Parkinson's for years and years and never been on medication, never going to, you know, a physical therapist who knows Parkinson's. Right. And just sort of resigned to the fact that, you know, yeah, I'm coming to see you, but you know, what are you going to do? And the answer is like, where do we start? Yeah. Cause there's always, there is always, always, always something. And we can always move the needle on quality of life. It may not be as much as we want, you know, all the time, every single moment, and moving the needle on every single symptom. Sometimes, you know, we don't want to make too many changes at once, because we might make something better and two other things worse.

But there is always something we can do. And I say this as someone, so my clinical practice currently, I spend one day a week running our AIMS clinic, which is a collaboration where literally that it's like a clown carb dumps us into the room with a person with Parkinson's and their loved ones. Sometimes it's a whole crew. But we have me as a movement specialist as our fellows. So, neurologists who are training to be movement disorder specialists and need to understand that what we think of as advanced, based on the literature is not the extent, right? So, it's a movement disorder specialist, a nurse who specialized in movement disorders, a social worker, a neuro palliative care doctor who can help with, you know, symptoms that might be



beyond my expertise, but can also, they are the experts at conversations to get to what matters most to you today.

Right now, is it, I really wish that I could still get to the lake and go fishing the way I used to. Then that's the focus of our visit. What do we need to do to make that happen? Right? And I don't care if you are in a wheelchair, I can make that happen. Right? We can make that happen. It's a question of pinpointing what is it that matters. And there are, you know, there are long and winding roads and there are all kinds of different ways to get from here to there. But finding a team that's going to listen to you and is going to work with you to actualize the goals that are most important to you, to your loved one, I think that's hands down the most important thing. Great. Awesome. Thank you. Yeah. So, this figure is from a paper that's now a couple of years old, but essentially just kind of puts into picture form this idea that, you know, we know a lot about the beginnings and earlier stages of Parkinson's.

There's a lot of focus. This is when most people wind up coming to care. But as time goes on, we see less, you know, of that less advanced disease showing up in the clinic. Because it's just harder for people to get to the clinic. And if you're not presenting to a clinic, which is where a lot of people get involved in research projects or hear about, you know, here's this support group, or here's this outreach event, then you're not even represented in the audiences in the support group to ask important questions that are pertinent and to make the team go, oh, wait a minute. You know what? We need to have resources available for folks who are dealing with this kind of thing or that kind of thing. You're not available to be recruited into even survey studies asking about, you know, x, y, or Z in Parkinson's.

So, there's this slope where people kind of fall out of the loop of care, they fall off the loop of research. And we only know about what happens towards the end where we may see, you know, publications saying, here's the rate of hospitalization, or here are risk factors for someone with Parkinson's being placed in a nursing home. But it is not a smooth transition between able to be in the clinic doing okay and then like, boom the next year. That that's not what happens. There is a lot of space in that slope, and we're trying to, you know, expand that, and understand what's happening there. So, we don't want anyone Wiley Coyote off of that cliff. We want to make sure that we're creating systems so people are not getting to that point and have a safety net for them. So, the long-term research questions that my group has been trying to answer are sort of who individuals are who are out there in the community not being reached by sort of traditional access to Parkinson's care. Who is supporting them, if not our outpatient movement disorders, neurologists, and general neurologist where are they? What are their living situations? What are their needs? What are their barriers? And why have they fallen into this in between? And how do we bring them back in? And our overarching hypothesis has been that it will require human connection to reach this population and interventions that leverage human connection to change that slope and change that trajectory.

So, one of the first ways that we tried to do this and this idea sort of came out and I was on faculty in New York and had the incredible fortune of working with a team who had recognized that, you know, they had these patients. And as movement disorder neurologists, we sort of become primary care physicians in a way. We build, you know, decades-long relationships sometimes, and we know our patients and families very, very well. And for a lot of us, we recognize like, wait a minute, I was supposed to see that person and they didn't show up or they canceled the visit, or wait a minute, you know, we'll just think of people out of the blue and go, I haven't seen them in a while. And so, Dr. Duroco, my chief at that time said, I want to find a way to reach my sweethearts who have fallen out of the loop of care and was fortunate, got a philanthropic grant and basically said, let's build a program.

Let's go meet people where they are, and figure out a way to do it. And so, what we did was we tried to, you know, say, if you can't come to the office, we will bring the office to you and then some. And so, a team of a nurse, a social worker, and either myself or a movement disorders fellow, again, because I want the people who train and come behind me to be better at this and have better training than I got. So, they came, and we went out to the homes of our patients in all five boroughs of New York City. So, if you were seen at NYU and your neurologist said to me, hey, I've got this person, I'm worried about them. I haven't seen them in a while, I'm not sure what's going on or why they can't make it to us. We went out and did home visits and I did all the usual stuff I would do in a visit.

I made you tap; I made you clap, I did this, I watched you walk. The secret sauce was in what our nurse and our social workers were doing, which was our nurse would, you know, sit with people, and say, take me to your meds. And if that meant that the medications are kept in a beer cooler and some baggies and a paper plate somewhere, we want to see it. We want to see the wrinkles and warts and everything. Let us walk around your home. Is it okay if we open this door? Can we see what your bathroom looks like with the goal of where are the preventable fall risks? Where are you most likely to get hurt in your home that would take you out of being able to stay safely in your home? And can we fix that before that happens? Meanwhile, our social worker would pull aside the care partner if there was a care partner and say, you know, what services are you currently receiving?

What services do you not have? And I think, you know, one of the, one of the things that was most salient to me is as a movement disorders neurologist, you know, we're taught, oh, well, you know, you have to be careful with, you know, food interactions with medications. Always ask your patients, you know, are they, are they taking their levodopa with protein? Right? Because it can interact. And that is true to some extent, but we had people who were referred into these programs and had listed in their chart, you know, this patient is medication non-compliant, they don't follow the directions of the provider. And we would walk into their home and realize that they lived in a studio apartment, maybe up five sets of stairs in New York City, and had no food in their pantry. And so that person, you know, hounding them about how close they were moving their protein related to their levodopa was completely missing the point this

person was medication non-compliant because they were choosing between rent and their medication costs, right?

And they were taking less levodopa than their doctor recommended because they simply couldn't afford a basic medicine that's been around since, you know, the 1950s, right? This wasn't, the person was actively making a choice not to behave and not to listen, right? And we never would've known that if we hadn't actually been, you know, given permission to come into their home and say, could we take a look around you to know, can we check out your pantry? Can we check out your fridge and built enough trust? And someone would actually let us, you know, be nosy and do that for that purpose of saying, you know, what the best intervention that we could do right now, can we get you meals on wheels? Right? And not only the food, but the social connection of someone else looking in on that family, you know, once a week or more than that.

That's gold. And I think levodopa is our gold standard and our best medication that we have, but that connection is even more useful and even more valuable. So, we did these visits, and what did we find? So interestingly we, this sort of table that I'm showing you is we kind of stopped at one point and just said, let's look back at the data. Let's see what we've been doing and who we've been seeing. So, we did an interim analysis in July of 2016, at which point we had done over 270 visits with 85 unique people between February of 2014 and the summer of 2016. And the mean age was 79.6, which makes us one of the oldest groups of people with Parkinson's that had ever been reported. And interestingly, even though we think about Parkinson's as a disease that's more common among men, nearly 52% of our group were women.

And I highlight this difference because, you know, it's kind of a change from what we're used to seeing. And also, despite the small proportions of non-white minority patients, sadly these numbers, 7% of our 85 people being black or African-American, and 7% identifying as Asian, those percentage numbers are higher than a lot of studies of people with Parkinson's. Recruited from clinics, recruited from the community. The median disease duration people had had Parkinson's for about nine years. And of this group. So, we sort of didn't limit it to Parkinson's within this first project. We said, we'll take anyone in the movement disorders clinics. So, most people had Parkinson's, but there were some folks sort of scattered in there with atypical Parkinsonism. And so, what I think is also really interesting and important to know is that nearly 50% of these folks had a part-time home health aide or some other caregiver, but nearly 13% of people that we saw in home visits lived alone and had no caregiver paid or unpaid.

So, Parkinson's that is so advanced that they met homebound criteria and yet had no one who was supporting them. We found that indeed if we built this program, people would let us come to them and they are out there. So, this is just sort of at that first home visit that we did, what stage were people at? And you know, this is kind of in, in drug study as they call it, sort of proof of concept or target engagement. Does the chemical, you know, bind to the receptor does go

where we want it to go? And we kind of found, you know, proof of concept is these folks are indeed out there and reachable if we go to them. And interestingly, I had been told by colleagues, you know, Jori, you can follow folks, but I doubt you're going to see any change over a year if you know, if you follow folks and do four visits over the course of a year, which is what we did for a small group of people who, you know, agreed to this you won't find change because if they're so advanced that they've qualified to be part of this program, they can't possibly get worse.

And unfortunately, this is a progressive disease and if something else doesn't get in the way first, the Parkinson's will progress differently in everyone, right? But it will progress. And what we found actually was there was a significant change in Parkinson's rating scale, both mobility mentation, cognition, depression, and anxiety, but the quality of life didn't change over the course of a year. Why does that matter? In every other study where people have followed sort of the natural course of Parkinson's, if Parkinson's, you know, severity is going downhill, like this quality of life tends to follow in parallel. But what we found was, well, disease severity continues to worsen, but we're seeing the quality of life stay the same. And so that was intriguing to us and said, well, maybe there is something happening here. So, there were challenges with this study design and as a scientist, sort of the scientific comments were, you know, well this was kind of a mixed population and you know, it was just one center.

Maybe you can do this fancy stuff in New York, but you know, how does this apply to other places? This is very costly. And there was no control group. So maybe it's not the home visits at all that was changing quality of life. Maybe if you just, you know, went out and you sent people and you dispatched them and you just measured quality of life without actually doing anything while you were there and you saw people, you know, four times within a year, you'd get the same numbers. And it's, it's true. We couldn't disprove that. And so, what we wanted to do was design a better study to really test this out. So, with through funding from the N I h and cure P S P, we launched a second study in Chicago and sort of a 30-mile radius, which actually includes suburban and rural areas.

So, people had to have Parkinson's and they could have dementia or not. This is a larger area. We looked at sort of the economic impact of this, and we enrolled dyads, meaning people who had a care partner who could participate. But wait, you just told me that there were people who don't have care partners out there. Yes, I know, and it is a huge problem. We are working on it. But from a scientific standpoint, when the reviewers are looking at things, they go, well, you know, you have to have everything the same. And you can't do something for care partners if someone else doesn't have a care partner. That's not, that's not scientifically valid, which is true. It's just realistically difficult. So, what we did in this study was we took our nurse and a research coordinator, and they went out to the home for four home visits.

Over the course of a year, I stayed here in my office with an iPad, and we brought a hotspot and an iPad to the person's home. So, we didn't have to worry about if they remembered their Wi-Fi

password. We brought her on WIFI. Our nurse did the same stuff that the nurse in New York did. She did the med rec; she did the home safety eval. She asked all the questions that we would usually ask in the office. Our social worker took the care partner aside, asked some of those questions, took the patient, the person with Parkinson's aside, asked some of those questions, and asked about the quality of life using Parkinson's, specific quality of life measures. And then the two of them phoned into me and said, okay, here's what we found. We think this is a problem, this is a problem, this is a problem. This is going really well.

They've got this in place, but maybe we could do this. And then I got on the call, did the taps, did the claps, followed up on other questions, and we came up with a comprehensive plan. And we left people with, you know, a written note that said, in really simple language, do this, start this, stop this. Here is your table of medicines. Here's how you're going to keep that straight, right? And connect it and maintain continuity of care. So, this is a very busy slide. What I want to say is, but what about the control group? How are you going to figure anything out? We really wanted to have a control group and we didn't think it would be ethical to say, all right, are you interested in a study of home visits for Parkinson's? Great. You are randomized to get nothing. So that was never going to fly.

And so, what we did instead was hope that we would be able to match our 65 individuals with Parkinson's, with someone from a larger national registry. And so, we said, all right, for every, you know, one of our people, we should be able to find a match in this registry you call the Parkinson's Outcomes Project. It has over 13,000 people with Parkinson's in it. They're followed annually over time. Surely we can match our 65 people to a handful of folks. You know, this person kind of has a couple of similar matches based on their age, based on their home in your stage three, four, or five. And based on their gender. And what we found actually was 26% more than a quarter of our 65 people had no matches out of 13,000 people. And most of the rest of the people had only one person who was sort of comparable.

What does that mean? What that means is what I told you in the beginning, which is that those 13,000 people who are being followed, there are lots of people at stage one and stage two and stage three, and they're followed for many, many years. They come back, they come back, they come back, and then they don't come back. And it doesn't mean that they're gone, it just means that they have been lost to follow-up. They're not coming in for clinical care. And that registry study is tied to, we do this research visit when you come for your clinical care. So instead, we said, all right, well just give us a group of people from there who are kind of similar. So, we compared our 65 to 319 people. And what we found was our home visit folks were older. We found a closer-to-expected gender distribution.

And so, 68% of our folks were male. 15% of our home visit population identified as black or African American, and 11% as Asian. And if we compare that to the 13, you know, the registry 96% identified as white. So again, we found that for some reason we see more diversity in our homebound population and a willingness to participate in research, but I would argue is pretty

invasive because we're getting up in everyone's business and coming into their house. And the big difference between these groups is we reached the people that we set out to reach. So, 63% of our folks were honing our stage four. So, using a walker using a cane 10, sorry. And 15% were honing our stage five at visit one, but most of our control group was stage three. So, we're really comparing apples to oranges.

But that's because there aren't any other apples represented. Well in other research studies, we want to change that. But all of these folks had caregivers and what do we find over one year just with these home visits? And then I'm going to get to the caregiver piece. So, what we found, again, using the same measure of the quality of life, that's Parkinson's specific, that's used in that long registry project that we used. So, if we look over here at what says pop control group, this, what does this number mean? What this means is in the control group, even though they were younger, even though they were better at baseline, their quality of life worsened over one year. But what we found in home visits was even though their baseline was worse, they didn't change over one year. And if we look at these different areas that make up the quality of life, so things like mobility, things like activities of daily living, but also the stigma, social support, communication, bodily discomfort, some of these got better.

So, speaking Melani, to your question about, you know, what can we do even in some of our most advanced folks, we can move the needle. And particularly I just, I think that this is incredible is in bodily discomfort. Our home visit population started with a worse sort of bodily discomfort score, 41.5 compared to 36.7 in the control group. And at the end of the year, their scores were better than that control group had even started at. So, we started off way worse. We ended way better. So, we can move the needle in lots of different ways. So, this is all lots of good background, but like what, so I want to take a moment to kind of set the stage about what do we know about caregivers' care partners. Sometimes I use those terms interchangeably. Who is supporting this hidden Parkinson's population? And the answer is family caregivers. So, what we know is more than 83% of community-dwelling people with Parkinson's and with Lewy body dementia rely on unpaid caregiving from family members which totals almost 19 billion hours billion with a b hours of care, which is unpaid for if we actually conservatively assigned a cost to those hours. That's 232 billion for the care.

What we know is that Parkinson's family caregivers have higher caregiver strain, caregiver burden, and higher rates of depression than caregivers of people whose loved ones have Alzheimer's disease or other related dementias. And there's been a lot of work studying family caregivers of people with dementia and less so in Parkinson's and some of the related disorders. But what we do know is that caregivers to people with Parkinson's have, you know, sort of score off the charts and all these different domains. And you

Melani Dizon:

Would, are you relating that to the fact that somebody, you know, as Parkinson's just has such a large range of symptoms, they're just so, exactly, all-encompassing?

Jori Fleisher:

Exactly. And I, you know, I've written articles on this, and you know, peer reviewers come back and they're like, well, well why, you know, why is this different? Why is this different? Let me show you back that slope before where movement symptoms are that part of the triangle and everything else Yeah. Is so much bigger. So, you know, for someone with Alzheimer's, their sleep might be a little bit disrupted, but not to the same extent as someone with Parkinson's. If your loved one with Parkinson's has REM behavior disorder and is waking up in the middle of the night and punching you in the face, or is wake up in the middle of the night, you wake up and they're out of bed and you need to go find them, right? You are not sleeping. Yeah. And that impact on that person's health and their caregiver strain is tremendous.

And that's one domain that's just sleep. Right, right, right. So absolutely. I, you know, it certainly seems like the combination of the motor symptoms, the cognitive symptoms, the non-motor symptoms, the mood symptoms, the constipation, the urinary stuff, I mean, everyone's Parkinson's journey is different, but everyone's Parkinson's journey has more than one thing, right? And that sort of synergy of all those things seems to be translating into an even greater ask of our family caregivers. Yeah. And I've, I've had people say like, okay, so caregiver strain is higher, but what about the person, you know, what about the patient? What about the person with Parkinson's? Is it reciprocal meaning like, yeah, so the person is, you know, more advanced that piles onto the caregiver, but then what, then what is, there is really good data showing that higher caregiver strain in a family caregiver of someone with Parkinson's on its own. When you statistically account for the severity of that person's Parkinson's, the worse off that caregiver does, the higher the chance that the person with Parkinson's will be hospitalized or placed in a nursing home. So, if we don't stop this cycle, it is, you know, it's bidirectional and it's harming everyone involved.

And but what about hiring someone, right? Would that be true, right? I think probably lots of people listening to this webinar are like, yeah, where are they and how, you know, why isn't my insurance covering them? You're absolutely right. So paid caregivers are not covered by insurance. If you're a lucky person who somehow has long-term care insurance, maybe you have some coverage. But for the vast majority of people in the United States, there is no coverage for paid caregivers, including Medicare, including hospice enrollment, which is a Medicare benefit. Paid caregivers are incredibly expensive. They're in very high demand and very low supply. And there is a tremendous turnover rate and a lot of burnout among paid home health. You know, caregivers, even pre covid. And what I've heard across the board from my patients, from my own family who's in a similar position, is you just can't find people.

Or you find someone, and something happens, life happens, and they need to leave. And who do I find next? And the hours that go into trying to find a person to take this burden off of the family caregiver is its own, you know, full-time job. So, I wish the cavalry were coming to answer this question of how do we help the family caregivers. You know, shouldn't the

government just pay for family caregivers? I agree. But until it does, you know, what are we doing? Who is supporting the family caregivers? And so, what we found in our home visits, we looked to see would home visits help answer this question. Not that they're the most sustainable option, but would this, would this move the needle? And in that first study that we did in New York, we didn't have a ton of people who had a care partner who agreed to answer our questions.

You know, four times over the course of the year, among those who did, we found that caregiver strain increased from mild to moderate over the course of that year. Interestingly, among a couple of people who started and then withdrew, they had way higher caregiver strain at baseline, which really makes us think, you know, this may be part of why they withdrew, right? But so, we concluded that home visits won't be enough because just that single touchpoint every four months, it's nice, but it's not sufficient. So, what interventions could be feasible and affordable and bring value to our caregivers without asking even more of them? And this led us to look to see what has worked in other caregiver populations. And one thing that's worked is an idea of caregivers supporting other caregivers. So, what we added to the peer to the home visit program in Chicago was this idea of peer mentoring.

So, peer mentoring is someone who has been there, who has been in your shoes, or may still be in your shoes, serving as a one-on-one mentor to the person who is going through the journey right now. And these programs have been studied in Alzheimer's disease, they've been studied in cancer populations, and they look different in different places and different disease populations. But in general, they have worked pretty well. So, we thought, well, why don't we try to do this? We recruited and trained 34 experienced Parkinson's or Parkinson's-related caregivers. We flew them or brought them into Chicago. We trained them for six hours, sort of making sure everyone had the same basic layer of knowledge about, you know, maybe your loved one has never had hallucinations, but your mentee's loved one might. So, let's just do sort of a primer on that. Or, you know, you might know tons about hallucinations, but constipation was never a thing for you.

Well, let's just talk about that in case it comes up. And then we gave them a very bare-bones handbook. And as our home visit, patient caregiver pairs were going through home visits. At the end of home visit two, we said, okay, we're wrapping up for the day. Here's your plan. Here are any medication changes. Also, here is the name of your mentor to the care partner. They're going to give you a call. We just want you to touch base with them. Ideally once a week for the next 16 weeks, you might find this booklet helpful. Might give you some conversation starters. Use it, don't use it. You do. We don't want this to be an extra ask. We want this to be giving you a lifeline. And here's what we found. So, 51 out of 61 eligible care partners said yes to it. Three withdrew.

Interestingly, we found among the people that were eligible and said no, their reasons were often, how could anyone possibly know what I am living through? You could not possibly, and

it's true, right? I mean, especially if you know, I'm the one or my nurse or my, you know, 20-something-year-old research coordinator is handing them this booklet, right? We cannot possibly know what it is like to wake up at 3:00 AM and find your loved one out of bed. Someone else has been there. And so, what we found was when we paired up our folks, we asked them to call each other. And despite everything they were doing and the 24/7 nature of being a family caregiver, it worked. They had a median of 11 calls over 16 weeks. We didn't give them a timeframe, we just said to touch base. And the average amount that people talked was 30 minutes a week, but sometimes 45.

And their satisfaction was 91 out of a hundred. We didn't find in this 16-week timeframe that it made a big dent in depression or anxiety or caregiver strain. But it's probably too small of a timeframe to tell, but at least what we saw was there may be something here. So, home visits alone don't change caregiver strain. But again, we compared it to that control group from that registry that's been going on. And what we found was the control group's caregiver strain worsened over the course of a year. It starts with their milder strain at baseline and their strain is still mild by the end of one year. But it did worsen for our home visit population. Their caregiver strain was worse at baseline, but it stabilized. So maybe this is sort of necessary but not sufficient.

So, we were really intrigued about whether this peer mentoring idea might work. And so, we moved on to a phase two sort of the phase two of this, which we called learning to persevere. And we took focus groups of some of those mentors, those 34 mentors from the first phase, some of the 51 mentees, and then some folks who hadn't been part of this at all. And we gave them the old handbook, which was, you know, 30 pages or so, not tremendous. And we had created a whole new curriculum we heard from our folks, but where I want to learn more about hallucinations or you need to tell me more about caregiver straight, or I want more resources on this. What's out there? I shouldn't have to go finding all these things. So, we created a phone book for people you could do your weightlifting with it.

And we recruited these focus groups of people, and we gave them the materials and we said, here's the old version. Here's a new version. Better, worse, the same. What do you like? What don't you like? What should we fix? And then we fixed it based on their feedback, and we started recruiting people to the second group of mentoring. We opened it up. So not just care partners whose loved ones had Parkinson's disease, we opened this up to Lewy body dementia, which includes Parkinson's disease with dementia or dementia with Lewy bodies, which is similar. But essentially the dementia symptoms come first and the parkinsonism, the movement, the slowness, the tremor that comes later or they happen at the same time. So, the symptoms are the same, and the timeline is a little bit different, but we sort of figured, well, you know what, this is a broader audience, but everyone is dealing with the same symptoms and can probably learn from each other.



So, with help from Parkinson's Foundation, I, the body Dementia Association and funding from the NIAM, we launched this study. We trained 36 new mentors from all across the United States, all virtually all on Zoom. We recruited 30 new mentees, and we asked people, you know, what do you think is important? We sort of made our own little caregiver Tinder, what do you think is most important to you in your mentor or mentee? And we put everyone's names on index cards and my team sat around the table and went, okay, this person wants to be matched with someone who has, you know, taken care of a loved one with early Lewy body dementia while also raising children, right? Is there someone in our mentor pool who'd be a good fit for that person? And we did the best that we could to try to match people up.

Never been a matchmaker before, but I think it went well. And we asked people than with this brand new, you know, giant handbook, talk with each other once a week for 16 weeks, fill out some, you know, surveys. Let us know how it goes. So, there's our little card-sorting task. And what we found was 30, our 30 pairs completed over 400 calls. So, for 16 weeks they talked to each other. On average, 15 weeks out of 16 for a median of 45 minutes, there is one pair that talked to each other for almost two hours every week. A hundred percent. When we asked at week 16, was this useful, a hundred percent found this useful, and a hundred percent would recommend peer mentoring to other LBD caregivers. And what was really exciting to us was knowing that the cavalry isn't coming. That there isn't some giant program on the horizon to suddenly pay for paid caregivers.

90% of our mentors said, call me in coach, like I want to do this again. Just keep my number, you know, I'm here when you need me. But 50% of our mentees said, I want to be a mentor next. I wanted to do this for someone else. And that includes while still caregiving for their loved one. We look to see did this actually improve any other outcomes. So, we created this Lewy body knowledge test and found even among our mentors, the green over here is the mentors. The experienced care partners whose loved ones may no longer be alive, they may no longer be caregiving, but they improved their knowledge significantly. And the mentees who are still actively caregiving improved their knowledge. They improved on this dementia attitude scale. It's their attitudes towards and their confidence in caring for someone with cognitive impairment. And we saw a little bit of an improvement in their depression scores.

So really compelling. And I think what speaks to me the most is hearing the words from our mentors and mentees themselves. So, we asked just, you know, tell us, tell us how it went. And from our mentors we heard, you know, I appreciate getting to know others that shared my experience. Doctors and nurses can tell me about symptoms, but one who lives it is truly able to comfort me. I think I helped my mentee. She certainly was a help to me. The team did an amazing job of matching. We had so much in common that was unique to our relationships. And this was a person who was really excited because they were on one side, one coast of the country and they helped someone else, you know, somewhere completely different. Being part of something outside of my four walls, gaining a friend, and realizing they had something to contribute.

We heard these echoed over and over again. And what's not reflected in the data so far, but hopefully will be published soon, is this study that 16-week study was over a year ago. And I hear from a lot of these folks, I take care of some of these folks. And some of them are just part of our research team and they tell me, oh, joy, I still talk with my mentee every week. And some mentors have switched their roles so that the mentee may have gone through the grieving process while the mentor had not. And the roles kind of reversed and the mentee was able to help the mentor and vice versa. And it's really spawned some beautiful connections. So other things that have also sort of informed this work are when we were trying to recruit people to be mentors or mentees, we were like, you know, there's all this data on, on the caregiver strain.

You know, we have this hypothesis that there are reasons why it's harder to be a Parkinson's caregiver than others. Let's ask our caregivers about their own medical problems. And I wonder whether there are certain things that they might have at a higher rate than other people. And indeed, you know, we saw our care partners in-home visits struggling to lift their loved ones. You know, so many times it's, you know, a spousal care partner and it's, you know, a wife trying to lift their husband. And that size difference, you know, muscle mass difference is really a challenge. And we found, yeah, that high blood pressure, and hypertension was much more common than they should have been. Depression, 35% back pain and 34% arthritis, and 33%. Those are much higher rates than they should be in adults of that age group. And among our younger adult caregivers.

So adult children, their rates of depression are much higher than sort of age-adjusted rates for someone who's in their thirties or forties. So, it is absolutely taking a toll and doing so differently. What we also heard was we would refer people in home visits and say, okay, we're going to bring in physical therapy to come to you. And we would get the feedback of, you know, thanks so much. It was really great, but I felt like I had to teach the nurse or the physical therapist about Parkinson's. They didn't seem to know this. So, we said, well, okay, can we use the training that we developed for our mentors? And can we teach that? We don't even have to tweak it. Let's keep it at a, you know, public-friendly level and see whether that actually makes a difference. So, we did. So, we launched it, we did it all virtually, and found indeed that we did that training. We incorporated some cool virtual reality training that's specific to Parkinson's and Lewy body and these 42 home health professionals, physical therapists, occupational speech therapists, and nurses, they over the course of six hours improved their pretest to post-test knowledge of Parkinson's in Lew body. They improved their confidence, caring for people, their comfort, and caring for people with a really quick, simple intervention.

So, the last step that we've had in the last couple of years was to say, we want to make this even better. We want to listen to our care partners who said, you know, this giant book is great, but it'd be really nice if it was a website. Why can't I just click through and get to the things that I want? You've given me links for great resources out there. It'd be awesome if I didn't have to copy that down somewhere. And of course, we agreed and just didn't have funding for it up until that point. But we recruited another giant group of caregivers who'd been through this

and said, let's revise the book again. You know, listening to the things that you told us you want in there. They wanted it to be 12 weeks, not 16, done. This should go here, that should go here, put this over here.

Done is this better? Did a bunch of focus groups. Great. Now let's take it, let's make it a website. So, we made it a website. Go use the website, care partners play around for a bit. And we used Google Analytics on the back end, and we gave them a scale. And lo and behold, actually it's a very usable user-friendly website. And we took this idea of that virtual reality technology to say, this has been tested. We've seen that this works to help home health professionals feel more compassion and understand what the person with Parkinson's is going through. Do we think that there might be any value in showing this to caregivers, either mentors or mentees, or both? So, we showed those videos to our folks and had them sort of go through it and they liked it. So, this is just a screenshot from the virtual reality. This is a screenshot of the website and it worked, and we took that and applied for a giant grant from the NIH to hopefully test this in a national randomized controlled trial of caregivers, family caregivers care partners of people with Parkinson's, with cognitive impairment, Lewy body dementia, and c whether this really works and whether this is a sustainable way to help people moving forward.

So, thank you. That is a long background. But hopefully, I've convinced you that while there are folks with home-bound Parkinson's who are out there and they're older and they're more severely affected and they're more racially diverse than those who are seen in the outpatient clinic, these home, these interdisciplinary approaches, including telemedicine, can keep people in the loop of care, can mitigate the decline that we see otherwise in quality of life and can mitigate caregiver strain through human connection. And that yes, our Parkinson's and Lewy body family caregivers have a huge rate of strain and burden and willingly learn and share their lived experience and wisdom as mentors and as mentees who are improving their own knowledge and attitudes and that of newer caregivers and willing to serve in sort of a pipeline of human connection to make things better for the folks who come after them. So, with that here, some of the awesome members of my team and funding thank you so much for listening and for the opportunity to share some of this work with you. And I hope we get to do more in the future.

Melani Dizon:

Yes. Oh, well, we definitely will. I am so excited about all of that. You know, I part of when I go through it and you're like, oh, you know, these numbers. And I think I think in so many ways that s that over the course of a year, they had moments where they were like, oh, I don't feel so alone, right? I don't feel as alone, and this person is here. And I have someone to pick up the phone and talk to. I have a team that I know is working on my behalf that cares. And I feel like it's, you know, likely that even, even given the ability to reflect and respond, those four times

per month can't capture it because they're still in the thick of it. They're still, it's just, it's, it's relentless, right? Yeah. There's no, there's no break,

Jori Fleisher:

Right?

Melani Dizon:

There's none of that. And so, I think it's like the data is showing that it's working and it's also showing that this is so big. This is such a thing. This is, there's so much going on. And that a year later I want to hear like, how are they a year? You know, like, what are they reflecting back on? Be like, oh, I didn't have that this year. And that was the really big difference. Like, I can reflect now and say, oh my gosh, I was so, I was in such better shape when I had that relationship and when I was getting regularly checked on. So, I think obviously there's always, there are always things that can't be totally captured. But I mean, I just can't, there's no underestimating how powerful it is for people to feel like they've got a partner.

Jori Fleisher:

Right. And I think a space to be able, you know, there wasn't a good way to kind of measure this, but did this give you a space to bring up things or symptoms or concerns that you didn't feel like you could bring up to someone else? Right. So, I mean, I know, you know, one of the symptoms, and again, doesn't happen to everyone because none of these symptoms happen to everyone, but there's something called delusional jealousy. And this is, you know, fascinating and heartbreaking at the same time. So, our people with Parkinson's can develop this fixed belief, this fixed delusion, despite all evidence to the contrary that their loved one, their partner, their spouse, or their significant other is cheating on them. And, you know, it's not something that is a movement disorders neurologist is in our routine checklist to ask about it every single visit.

And if no one has ever asked you about that or explained why they would be asking because that's a part of the disease, you would never necessarily know that that's part of the disease. And I have had care partners who tell me, you know, when I bring this up and say, have you ever had this experience? Have your, has your loved one ever accused you of, or hinted that they might be worried about or this, and just this look of like abject, like shame and guilt and the scramble to go, I'm asking you this because this is part of the disease. This is not you. And I mean, I had families call in during lockdown, you know, my loved one swears that I'm cheating on him or I'm cheating on her. I haven't left the house in four weeks. Right. I've been at their, you know, I haven't slept like, how could I possibly, I'm like, because you haven't, right, right. So just to be able to pick up the phone, you know, and have someone and you know, be able to say my loved one thinks that I'm cheating on them and not have them go Well, do you think-



Melani Dizon:

Yeah.

Jori Fleisher:

This happened to me too. Yeah. Oh my god. You know?

Melani Dizon:

Yeah. And you know, if you don't know that your approach might just be to defend yourself and try to explain all these reasons why you didn't do it, and versus knowing, knowing that this is just the disease and there's really this is a fixed belief. Like you're nothing you say,

Jori Fleisher:

We're not going to argue out of the belief.

Melani Dizon:

He's going to get it. So, here's a different approach. Right, exactly. Okay. Like, I'm, you know, right,

Jori Fleisher:

Right. Yeah. This happened to me. And when, you know, he or she would say that here's what I did instead. Right. That is so much more helpful. Yeah. Then like, you know, Googling or, you know, anything or trying to prove to the person it's not going to work. Right. You need like real-life strategies to say, I've been there, I've done this, I tried this, and this, you know? some days this worked, other days not at all. Right. So,

Melani Dizon:

Yeah. And I think that it's that piece you said nobody is No, you couldn't possibly understand. Right. That's the thing. Right. Nobody understands if you weren't a caregiver, you can't help me if you'd didn't have this specific experience, you can't help me. And for some of those, some of those you can't turn. Right. Some of those, you just, you can't, you can't turn them. They, because on some, you have to be open to it. Right. And I think that happens in so many other areas of life as well. They say, well if you didn't go through this, you can't help me. And that is one way of approaching life. Right? Right. And so, we, yes, these are Parkinson's care partners and caregivers, but they're also humans who, when, well, maybe it was something else, they would've had the same approach.

Right. Right. And so, the best that you can do is say, well here's, here's what I have to offer. Do you want it? You know? Right. Or do you not want it? And, but I think that that dyad piece is just so, so good. So good. Was there anything, I mean, it's, it's so interesting the, from 2014 to now, right? That progression of, well, we're going to add this, we're going to add this, we're going to add this. Yeah. What was sort of the most surprising thing that you've learned throughout this process?

Jori Fleisher:

I think, I mean, just how much, how much more information people wanted and how for people who even have been caregivers for years and years and years, their loved one may have passed on, that we would cover stuff in the mentor training or, you know, things in the handbook. And they're like, I never, no one ever told me this.

And for so many of those, this is, this was in there because another caregiver in the prior iteration had said, sure, you have to add this in. No one talks about, you know, urinary dysfunction and no one talks about, you know, changes in sense of taste and how that impacts how people eat, or that the unintentional weight loss isn't a reflection on you as a cook or as a caregiver. You're not feeding your loved one enough. Or just all of the complex emotions that caregivers can go through, you know, and you know, folks calling out, this was so helpful, you know, add more, add more, add more and more. And we kept saying, you know, but it's huge. And they're like, doesn't all exist in one place.

Melani Dizon:

Yeah.

Jori Fleisher:

And to have something to be able to go back to, you know, and to,

Melani Dizon:

You may never open that page; you may never have to open that page. Right. Yeah. Exactly. Yeah. I, my, my thing with like workbooks and our, even our ever-read accounts manual and everything, everyone's like trying to turn it into, well, we do this curriculum. Like no one wants an A in this subject. Nobody wants an A in care partnering, or nobody wants an A in Parkinson's, but we can give them the resource so that on that chance that they can look up an index and say, oh my gosh, it's right there. Right. I feel like, oh few. Right. Yeah.

Jori Fleisher:

I mean, and just, you know, that diversity of opinions, right? Is we heard from people; I want a comprehensive list of every possible symptom that could never happen. And other people were

like, yeah, okay. Put that in the back. Yeah. Right. Because some people, they want it, and other people are like, I would like to take it as it comes, or I would like to, you know, bite off this chapter first. And so, you know, it's never, there's never going to be a perfect intervention, you know, that is so delineated and directed. I think that serves everyone because people are too different. Yeah. And this disease is too different and people, you know, everyone's needs are unique. Yeah. And or even the same subject matter, the order in which people need to hear it and learn it and absorb it's different. So

Melani Dizon:

Yeah. I think, and that's, you know, obviously one of the reasons why the website can be such a big help, right? Because it's, I filter it and I can find what I need quickly and it's no mess, no fuss, and yeah.

Jori Fleisher:

You don't have to take a quiz to get to the next chapter. No, we're not.

Melani Dizon:

So, for all of those home visits that you did, and I know that you took an iPad and a hotspot, but what percentage of them actually didn't have internet, like couldn't have accessed the website?

Jori Fleisher:

That's a good question. I don't know. The exact number. I would, I would estimate we were somewhere between like 15 to 20% and that was, so that was all pre-pandemic., you know, there's, there's good data showing in general in the population that during the pandemic there's been some improvement in like this digital divide. So, people who didn't have internet, more people have it now than those who didn't before. But, you know, being in a place where you could get internet or where you could pay for internet is different than being able to use it, access it, you know, not be concerned about it. Right. And use it for, you know, getting healthcare and things like that. So, I think we're still a ways off. and you know, I followed a lot of my home visit folks from Chicago after sort of the study ended because it, that limited funding we did follow people out just by calling them six months later and a year later to say, you know, how are you receiving care now?

Because we thought people would go back to, you know, seeing their neurologist from whom they came or things like that. And it turned out most of those people were like, Nope, we're, we're sticking with you. So, a lot of them we didn't really need to call because they just stayed on as my people. And then thankfully, you know, with, with improvements in telemedicine, we were able to see a lot of people. But I have folks who, you know, I've never physically met who came to me, you know, and I met them in 2018 when my team was out there at their house

and I met them on a video visit, saw them for a year in video visits, and then the pandemic hit and have only seen them on video or sometimes by phone, you know. And so, they're folks that I haven't seen their face in a while because they just, they don't have someone who can reliably help them or, you know, come to their house, and bring an iPad or something else. Right. They still deserve care just like everyone else. Yeah. So, yeah. Yeah. Just a plug to, you know, call your congressman, call your senators, call everyone, and advocate that we still have access to telehealth beyond, because it's like we finally made some gains Yeah. In being able to not reach everyone, but to reach more people who were unreached before. Yeah. And that access is threatened, you know? Yeah. Going forward. So,

Melani Dizon:

I mean, I think the thing that I of so much about the, all the studies that I find fascinating, interesting, and love it. But the one thing that has just captured me from day one that we talked about, it was this whole idea of, oh, we found people by finding out who canceled their appointment and never came in. It's like, ooh. You know, like how many of those are out there that have just said, you know what? Nothing's going to happen anyway. Why am I going in like,

Jori Fleisher:

Right. And it was hard to find those people. So, I think, you know what folks may not understand is like, I wish that, you know, people ask me all the time like, well, how many patients do you take care of? I have no idea what the number is. I don't actually know. And I've tried asking, you know, folks, and I've worked in a big academic institution, you know, can you run a list? We have an electronic medical record, we, you know, key in all these things. You've seen us in the room, how you bring the whole time trying to get stuff in. Right. It is really hard to get answers to those kind of questions. You know, how many people have I like really been part of their care or, you know, they were supposed to see me, but then they need, you know, they never showed.

It's really hard sometimes to get those numbers and to try to find people where we were, you know, trying to pull lists of every one of my colleagues, patients who they've seen in the last couple of years, and then have, they had gaps, right? Is really challenging depending on the healthcare institution and the electronic medical record and all of this kind of stuff. So, you know, don't, don't fall in the cracks, I guess would be the message. Right. And your doctor, you know, your healthcare team is not actively trying to forget about you if you feel like, you know, you haven't heard from them. I think the staffing shortages in healthcare during the pandemic have been just beyond overwhelming. And there was a point where, you know, we're supposed to have six cl, you know, people just to help us with scheduling. We were down to one. Right. And so, people were calling in for appointments and just one person could not respond, right, to 16,000, you know, voicemails. And so, people went, you know, for a while and it was like, I promise we want to see you. We are worried about you.



Melani Dizon:

Right.

Jori Fleisher:

Please be the squeaky wheel. You know, you shouldn't have to be. You should never have to be, but don't, you know, finding some way until the system works better to not be left out and to not be forgotten. Yeah. Please speak up. You know, your team wants to see you. We think about you when we are not seeing you, so.

Melani Dizon:

Right. And just one more question, just cause of curiosity. Did you do I mean; I would assume it was relatively low if non-existent, but for all of those home visits that you went to, were any of those care partners, or caregivers part of any group whatsoever? Any sort of support? Had they been and then they stopped or was there, or were they just really never part of the community?

Jori Fleisher:

That's a good question. We didn't specifically ask the care partners that as far as I can remember, we may have, but I haven't run the data yet. We have reams of data. Right. But I think a lot of people were or had been parts of support groups at some point and then may have sort of fallen out of the loop of care. You know, what I hear from people sort of on both ends is if you are really early on in the Parkinson's journey and you go to a support group and you see folks who are farther into the journey, it is understandably, you know, it can be really scary. And so, people may not go back. Similarly, if you're on the other end and you're going and you're going and you're going and you're seeing more people come in who are so much earlier on the journey and sort of reflecting back as the person with Parkinson's and going, you know, that used to be me or, you know, the care partner going, you know, that person reminds me of, you know, way back when. I think that can be really hard as can just getting to the group for some people. And so especially for groups that weren't, you know, didn't have a virtual option pre-pandemic, there were a lot of folks that had been part, you know knew our, knew our nurse's names who had run. Right. And would say, you know, I used to go to that but hadn't and some time. Yeah.

Melani Dizon:

Well, I really appreciate you taking the time to talk through all of this, and I'm excited to see what's next in the research area and then what we can do together for our care partner community.



Jori Fleisher:

Thank you so much. I can't wait. I'm just thrilled to have the opportunity, so thank you so much.

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