Michael J. Fox: This is Michael J. Fox. Thanks for listening to this podcast. Learn more about The Michael J. Fox Foundation's work and how you can help speed a cure at Michaeljfox.org.

Speaker 1: Navigating Parkinson's disease can be challenging, but we are here to help. Welcome to The Michael J. Fox Foundation podcast. Tune in as we discuss what you should know today about Parkinson's research. Living well with the disease and the Foundation's mission to speed a cure. Free resources like this podcast are always available at Michaeljfox.org.

Lydia Chain: Hello and welcome to The Michael J. Fox Foundation's Parkinson's podcast. I'm your guest host, Lydia Chain. I'm a senior content producer here at the Foundation, which means that normally I'm on the other side of the mic. I work behind the scenes on resources like our third Thursday's webinar and this podcast to share the stories of people living with Parkinson's and interview experts on living well with the disease and the latest in Parkinson's disease research.

During the month of June, many local, national and international groups celebrate pride to honor the contributions of the LGBTQ+ community to history and society. It's also a moment to draw attention to the many places where inequality or information gaps linger. And one of those places is about Parkinson's disease. I'm queer and trans. This is an issue that's close to my heart and there's a lot that we're still learning about what it's like to live with PD as part of the LGBTQ community and how to design PD treatments and care systems that work for everybody living with the disease. So without further ado, I'd love to introduce our esteemed panelists. Jason Flatt is an associate professor at the University of Nevada Las Vegas School of Public Health. They lead the Parkinson's research with inclusion, diversity and equity pride study, which looks at the health concerns and needs of LGBTQ people living with Parkinson's, their care partners and their healthcare providers. Welcome, Jason.

Jason Flatt: Thanks so much for happening me, and happy pride.

Lydia Chain: Great. Yeah, happy pride to you too. Stephanie Smart is an embodied movement specialist, a parent and wife, a nature lover, and an exercise enthusiast who is diagnosed with Parkinson's in 2018. Welcome, Stephanie.

Stephanie Smart: Thank you. Thanks for having me. It's an honor to be here.

Lydia Chain: And Bernard Whitman is a brand and political strategist, an author and a husband. He was diagnosed with Parkinson's in 2017.

Bernard Whitman: Thanks so much for having me, really appreciate being here.

Lydia Chain: All right, there's a lot to cover, so I want to jump right in. Parkinson's disease journey is going to be different and symptoms of course are a part of that, but it also includes other factors like how different the experience might be of living in a city with a large medical center versus living in a rural community where your doctor might be hours away, or how different families and cultural communities go about supporting a person living with Parkinson's. Jase, what does the research say about how being part of the LGBTQ+ community impacts life with Parkinson's disease?

Jason Flatt: Yeah, so LGBTQ+ people really have unique circumstances that can impact their experiences both with the disease, but how they seek care. We know they're twice as likely to live alone. So right there, when we think about getting support for care, maybe getting to the doctor, we also know they're less likely to have children, they're often less likely to be married. And many community members experience unique challenges. They have likely grown up during a time where they did not have equality, so protections for things like housing, for their jobs, but even things around healthcare.

So for many people living with Parkinson's, they may be reluctant to seek out healthcare when they're having a problem. Maybe they've been misgendered before. It also could be fears around getting lower quality care when they go to a provider. And bring that into then, the unique challenges around maybe they're aging with HIV, maybe they're a transgender person and they're fearful about the laws in the state that they live in terms of really being able to receive gender-affirming care. So it intersects both in terms of people's identities, but also they're unique life circumstances.

Lydia Chain: Thank you so much, Jase. And you're so right. Every person living with Parkinson's is going to be bringing their own background and their own set of life circumstances to this event. Stephanie, how does that resonate with you? How does your sexuality intersect with your Parkinson's and how you get care?

Stephanie Smart: It does resonate, absolutely. And I live in a state where I don't always feel included or inclusive. And so, when I show up at an appointment and I show up with my wife or I use the term my wife or mention my family, it absolutely plays a role. And I have to think twice every time I try to have a conversation. And even if my individual provider I know is completely okay with it, every person in the office, I have to have that conversation again and I have to worry, is this going to be an issue?

Lydia Chain: Do you feel like your care was impacted at all by the fact that you were a lesbian?

Stephanie Smart: I can always question that. I think with my initial diagnosis in 2018, it absolutely did not. But I showed up at neurology with tremors and other symptoms in 1998, and I was misdiagnosed and continued to be misdiagnosed. And I always have to question, was it because I was a woman, because I was overweight, because I was a lesbian, because my wife showed up? All of those things, how much did that impact that conversation and that diagnosis in that office in a state where I am a minority?

Lydia Chain: And that's just exhausting to have to walk through as you're going. Bernard, what about you? Have you had any experiences like this?

Bernard Whitman: I mean, I've been very, very lucky. I live in New York City and I haven't had that sort of fear or that concern about how I will show up that I think is very real in many parts of the country. But let me go somewhere, and this might be a little controversial, but it was my experience for me personally.

I think one thing to understand, we all know is Parkinson's experience is different. If you know one person with Parkinson's, you know one person with Parkinson's, I think for me, key to where I am today was accepting the diagnosis and I can just be flat out honest. When I first got diagnosed Parkinson's, my grandfather had Parkinson's, my uncle had Parkinson's. Parkinson's is stereotypically an old person's disease. It also makes you feel old and some stereotypes have roots in some reality.

I was very concerned about my, as a gay man living in New York City, young, vital, what does that mean for my body? What does that mean for my physicality? What does that mean for my attractiveness? What does that mean for my sexuality? What does that mean for all sorts of things that are external that people maybe judge you on, maybe you judge yourself on that? We were inundated, of course, in this community, particularly when gay men with the perfect bodies and obsession with body culture and so forth, and I thought, my God, what am I going to do? And that took a few years of understanding that keeping this wall up and this fear that it was going to somehow redefine who I was and negate who I was as a person. Getting over that was the biggest moment of freedom I had.

Lydia Chain: That is a really important point, especially about how all of our identities impact each other, that being LGBTQ or being part of that community might impact your care, but also having PD might impact your identity as a gay man and the way that you want to live your life and the freedoms that you enjoy. Jase, I want to get a little bit deeper into some of these things that you're bringing up. Let's go into first that diagnosis and treatment bit. How does bias lay it part here?

Jason Flatt: I think one, there could be bias in terms of... I think we heard from Stephanie a little bit. Maybe they blame you a little bit for whatever your health problems are. So you go to the doctor and they're blaming you for health challenges you have. So an example, let's say you're a person aging with HIV and you have Parkinson's. And they may not initially either look into those challenges or they'll think like, Oh, this is because of the medications, or this is a part of how you age with HIV. And so, it can create some really unique challenges.

There's also bias in terms of, I think Bernard brought it up a little bit of a fear around the loss of autonomy. There's a fear of if I go to the doctor and they give me confirmation that I have Parkinson's disease, what happens to my life? So I know a local community member who got their diagnosis and then were afraid, Can I keep my job? Am I going to be able to drive? Am I going to be able to stay in my home? How am I going to navigate all these pieces in my care? And then you may live in an area where you don't have many movement disorder specialists, so how are you going to get specialized care? How are you going to find out about the novel treatments that are out there? Can I get in a clinical trial that's testing a new treatment or can I afford the medications that I will need?

So there's a lot of complexity in it. There's the part on the medical side that is incredibly complex to navigate. And then there's the challenges that the person is having with either not having that diagnosis yet and navigating the symptoms or having a diagnosis and now fearful of what comes next. And so, it's a really complex piece and I feel that the field right now doesn't do enough to think about the social and emotional aspects of the disease. How do we support people fully, not just with the diagnosis and potential medications, but how do we support them to have the best life they possibly can have? And those are major fears that I often hear both from LGBTQ+ living with Parkinson's disease, but also their caregivers when they're navigating these challenges.

Lydia Chain: Yeah. That makes a lot of sense. I'd love to actually turn to Stephanie and Bernard here to talk about some practical measures that each of you have taken in the areas that you mentioned. Stephanie, what really helped when you are in that doctor's position and you're having to explain yourself again, is there any strategy that you'd suggest our audience can use? How have you navigated that?

Stephanie Smart: I think the biggest piece is to trust yourself. Trust what you know, because you live in your own body and you're the only one who lives there. Just like Bernard was saying, one person with PD is one person with PD, and we have to advocate for ourselves. And I think that's the biggest place that we as a community lack. We do not teach or enable the skills to be advocating for ourselves. So when I showed up for the movement disorder specialist in 2008, and I told the whole story of my previous 20 years and her initial is, "Well, it could be initial essential tremor." And I was like, "But look at this and what about this and what about this and what about this and can we try something? What's some options?

And I just opened the floor and then we had a conversation. And I think that's the biggest piece is participating in the conversation as an equal because you are the expert on your body and they may be the expert in Parkinson's as a whole. And I think showing up in that relationship is really important. And I think when we can bring our partners with us in whatever form they are and helping to model that, it supports your partner or your spouse to show up in those conversations as well. And for me, she said, "Okay, well let's try some medication as though you had Parkinson's." And it was life-changing for me. I tried Sinemet and I sat and cried because I actually felt like I got my life back and that wouldn't have happened had I not advocated for myself. And I think that's the part that it's the trusting ourselves that's so important.

Lydia Chain: Yeah, really, really important part about self-advocacy and also links to what you were saying, Bernard, about moving through your community with PD. And I'm really curious what strategies you've used to navigate. I've heard a gay man once talk about how when he got diagnosed with PD, he's like, "Oh no, another thing I have to come out about." Is that something that you experienced?

Bernard Whitman: That's actually hilarious. I had not thought of it. 100%. I hadn't thought of it in that way, but it's so true. And that's what Stephanie was getting at as well. You have to come out over and over and over again. But I will say this. Probably the most important powerful lesson I've learned is what Jason and Stephanie had been talking on, that is it is so critically important that each person on this planet understand how to advocate for themselves. In the healthcare system we have today in the United States, you can have, as I have, incredible advantages. I had advantages at geography, I had advantages in education, I had advantages in access. I had advantages in time, I had advantages in independence and freedom because I own my own business.

Most people don't have any of those, many people don't have any of those. I felt so alone so many time, and I thought to myself, my God, I have every advantage possible. And it's still so hard to navigate the system because it is disparate, it's disconnected, it's disjointed, it's not easy, unclear. And to Stephanie's point, you really have to know your body because you have to advocate at every single moment.

Nd I think to myself, the one thing I think that Michael J. Fox Foundation can really do among others, one thing in particular is establish a benchmark of standards, standards of care, and have, I think every center of care should have a care manager so that you can walk through someone's disease journey and connect all different parts, because moving disorder specialist key, physical therapist key, medicine management key, education key, resources, surgical interventions, so many things and keeping track of that I think is extraordinarily difficult. And with being gay or any of marginalized community, you have that much more difficulty in wading through things sometimes.

Stephanie Smart: I want to tag on to what Bernard was saying, that even having a care manager, I ended up at a Center for Excellence at Parkinson's Center for Excellence. And even with that and finally going to some PT, I had no idea that executive function and multitasking was part of a presentation of this disease. And I think that we don't list all those pieces that could be that help people think about things, because even if I end up at a place where there's all those resources and I have all the privilege that I could have, I still don't have the tools to be able to get there.

Lydia Chain: All of you at some point in this conversation have referenced care partners as a really important part of your strategy for managing your life with this disease. And I want to get a little bit deeper into that. I'm going to start with you again, Jase. You mentioned that people in the community are two times as likely to live alone.

Jason Flatt: Yeah. For LGBTQ+ people, there are two times as likely to live alone compared to non-LGBTQ+ people. And I think it's also, it may be double or a little more in terms of being single as they age as well, and then they're four times less as likely to have children compared to non-LGBTQ+ people.

Lydia Chain: And how does that affect how we think about care?

Jason Flatt: Typically your caregiver, if we think about it in the traditional work when we think of family caregivers is going to be your spouse or partner or your children or some other family members. But for many LGBTQ+ people, especially as they age, and given our sociopolitical climate at the time when they came out, more than likely they were ostracized by their family. So they're disconnected.

For many people, their parents have already passed, but they may not be close with their siblings, and like I've said, they haven't had children. And so, that creates, while we have a unique piece in our community of we have chosen family members. These are friends that we have had for decades. I can think of some of my own best friends that I can rely on. They're my emergency contact sometimes unless I'm... Of course my husband is usually my emergency contact, but if I needed another friend, I have a 25-year plus friendship with someone, that would be my contact.

But the issue too is many of us move across the country for our careers. My best friend actually lives in Chicago. I live in Las Vegas, so that makes unique challenges when we think about that. So if they're fortunate to have a caregiver, so a spouse, a partner, maybe it's a biological family member or a chosen family member, usually that's the only caregiver. So that person is taking on a lot to navigate that care. And then when they go to seek out services in the community, either for their care recipient or for themselves, there's all these eligibility criteria that are based in a heteronormative environment of you either have to be married or you have to live with the care recipient to be eligible for the services.

And so, that is not what we're often finding for LGBTQ+. People living with Parkinson's disease, often their caregivers are a close friend, maybe a relative, and they often live in another state, so they're caregiving from a distance. If they're fortunate to have a spouse or partner that can help, it's really hard and experiences vary both geographically, where you live, the state in which you live, but also if you're living in a rural community or in a city, it also varies. And so, there's definitely some unique challenges. And from our study, one of the big pieces that came up was around service gaps. There is this scarcity of services and support for caregivers of people with Parkinson's, but especially LGBTQ+ caregivers. And so, these are some areas that we just need more research, but we also need more services and work to make those services really inclusive.

Lydia Chain: Really good to know. Bernard, how do you and your husband think about care partnership?

Bernard Whitman: I mean, I'm so fortunate, so incredibly fortunate to have a husband of 11 years that I count on him multiple times per day. And I think there's no other visual element that I can share with you today than shortly after my surgery, it was very difficult, my DBS surgery, and we had gone out for a brunch and it happens to be in the middle of July in New York City, it was very hot. And we went to a nice place. I wore long pants and we got there and we had a wonderful time, and then I got stuck and I couldn't walk. Terrible gait freeze. And then when I say I couldn't walk mean it was really bad. So it took about an hour, place was a block and a half away. To get half a block, took an hour.

And finally to cross 8th Avenue, 14th and 8th Avenue, Constantine picked, Constantine picked me up and put me on his back and he carried me across the street. And he put me down the other side and I thought to myself, My God, I have come a long way because the idea of being carried on someone's back, even my husband's back even a few years earlier, as again as a gay man would have meant I would've been devastated, and I didn't care because I trust him so much. We've been through so much together.

Care partners in whatever format, whether husband, child, wife, son are so critically important and really need to, I think as a community, both LGBTQ community and a Parkinson's community understand and really appreciate, but also educate both those living with the disease and those potential or actual care partners, because they require a lot of support. And sometimes I don't even know how to do that. I could actually use guidance on how I can better support my husband in supporting me.

Lydia Chain: Stephanie, how about you? How does your care partnership look like and if you have ideas about how you support your care partner?

Stephanie Smart: Yeah, so I might be the dissenting voice here. I was 34 when I started having tremors and I was in school in Chicago, so I was living half time every week in Chicago, and then every other week I would drive back home and forth home to Indianapolis. And then we had kids and I became the person who was the primary stay home person, and I worked part-time in my own business. And so, I spent the majority of my disease presentation as the primary caregiver for my family.

And so, I don't actually like the word or the term of care partner or caregiver in relationship to a partnership like this. And that's because I think for me, it feels very disempowering for my own journey. And I think it also alienates a partner. However, whatever term we want, a live-in partner, a friend, whoever is going to be that partner for you in your disease discussions and progression, I think it disempowers them and doesn't make a door opening if you are a slow progression or you're a young onset who isn't having a lot of issues.

And so, in my house, I'm the one who is mostly doing for everyone else. We just had water main break in our summer place and I'm the one out there digging the trench while they're all working or doing other things. And it doesn't mean that my wife could not use support. It doesn't mean that there's not things that are built into our family at this point that I need help with. And because of the way that we term care partner and how it's discussed in the greater community of Parkinson's, she doesn't feel like she's welcome or that she would be able to benefit from any of the resources that are out there, because she's not really caregiving to me. We've just worked out where I have balance issues.

So if there are stairs, my entire family knows they need to be right there and be my handrail if there's not one. And it's built so seamless because we talk about things and because I advocate for myself, and we've got that culture in our household. And at the same time, I don't like the term of I need a caregiver because it makes me feel like I'm not powerful in myself and I'm not able to take care of myself in ways that I can. And so, I just think that we need more of a partnership piece of it.

And there's a term that I have used throughout most of my adult life and with my wife and that is that we talk about being each other's allies and it's inherent that if she is my ally, I can always trust her. And all of the things that Bernard was talking about and letting his husband carry him, that inherent component is built into that terminology for us. And that piece for me to shift from being a caregiver and a care partner, those things just don't work. That's not a dynamic that works at this point, and I don't like how we use it in the greater community.

Lydia Chain: Yeah, thank you so much for sharing your perspective. I think that there's so much nuance here that we could get into if we had a little bit more time. I love that you're pulling it back to this idea of advocating for your needs and doing what works for the two of you. Even if being carried by your husband, Bernard, it isn't necessarily what you'd anticipate or expect going into it a few years back.

Jason Flatt: I wanted to comment on something that... So Stephanie, first, I really love the word of ally, and that makes a lot of sense, and so thank you for sharing that. But I think another thing that we found from our research that I wanted to point out is that people get a lot of meaning out of this. So those who are helping with care, it's not all bad. We heard stories about how honored people feel, how much reward they get from helping with the care. And so, there was, for instance, a story of a person that was helping to care for their grandmother, and that they actually cherish the time together. They get positive feelings, they bond, they feel good, that it is mutually rewarding. And so, often I think we often focus on more of this deficit lens of like, Oh, they're giving care. It's such a challenge. It's so hard on them. But there's also this restorative and rewarding piece to it that we often don't talk about, and we're hearing a lot from the LGBTQ+ community. I just wanted to share that.

Lydia Chain: Thank you for that, Jase. Yeah.

Jason Flatt: Yeah.

Lydia Chain: I want to go back to you here as well. As we're talking about mental health and the ways that we walk through life, there's this question that we have about overlapping symptoms and concurrent conditions. What do we know about mental health in the LGBTQ community and how does that link to Parkinson's, which has known mood associations with it?

Jason Flatt: More broadly for the LGBTQ+ community, we see worse mental health, and I often hate just leaving that alone, because it sometimes can be used to blame the community in terms of maybe these are the reasons why they're LGBTQ+, but that is not. They're navigating a world where they're not treated equally, they experience discrimination. Just even having to navigate or be afraid that someone might call you a name or mistreat you having to be vigilant about, Oh, what is going to happen to me? Am I safe? That is a hard piece to navigate through life, and obviously that is going to impact people's mental health.

So we see some concerns for LGBTQ+ people with Parkinson's disease as well, similar to those without Parkinson's in the LGBTQ+ community, there are higher rates of depression, there are higher rates of stress. We see greater concerns with things like post-traumatic stress disorder, PTSD. In our study, we did do some measures to look at both depressive symptoms and also... So we didn't find... It was higher, but not at a rate that was what we would say is statistically significant. But we did see a higher score in terms of depressive symptoms.

What was really concerning to me was more around anxiety. We saw really high rates of anxiety among LGBTQ+ people with Parkinson's compared to non-LGBTQ+. And so, I don't exactly know why that is, but I think today we've been talking about some of the hardships that the community has to endure with their Parkinson's disease, both socially, but in the seeking out care and navigating it with our families and all of those pieces. So I think that that helps to explain maybe some of it, but there are definitely in the research, there's concerns of mental health for LGBTQ+ with Parkinson's.

Lydia Chain: And speaking a little bit more about your research, why is this an important thing to study?

Jason Flatt: I think it's important one, so that we can understand that maybe care approaches need to be a little bit, both from your providers in terms of thinking about the unique mental health concerns, but also to understand how is mood disorders and related, how are those tied to Parkinson's disease progression? We need to really be thinking about promoting quality of life and so ensuring that people get the best care that they can possibly have. And so, this is going to require a more holistic approach when we think about treating the disease, both in terms of mental health, I've already talked about, I'm a big person on social aspects. Also, the movement related pieces, so the physical body as well. It's an important piece that I think we need to consider.

Lydia Chain: But sometimes that data is really hard to come by.

I do want to give a little shout-out here to the Parkinson's Progression Markers Initiative or PPMI, the Michael J. Fox Foundation's Landmark study. The study added optional sexual orientation and gender identity questions in order to improve inclusivity and address the complete needs of this population. It's a really valuable study that it has already yielded important understanding about Parkinson's disease, and it recently expanded its eligibility criteria. To learn more, visit michaeljfox.org/podcast-ppmi. I want to go in a little bit more in-depth here about what some of these barriers are to research. Why is it difficult to get this information?

Jason Flatt: Yeah. Well, we've actually leveraged some of from the Fox Insights data. We did a study where we looked at differences by sexual orientation, gender identity, and then experiences, awareness of and attitudes towards research. And there are some unique pieces. So one of the biggest is that LGBTQ+ people are worried about how they're going to be treated when they go to a movement disorder specialist. But also just in terms of what we heard from them, a lot of them having to teach their providers about the care that they need. And so, that has been a huge challenge. There's also, we've talked about some of the barriers. One of the significant things that we found for LGBTQ+ versus non is that distance, getting transportation to a movement disorders clinic is one of the common barriers for them to participate in research. So there are a lot of really unique pieces in terms of this.

I've shared more likely to be unemployed, maybe to have a lower income. They often have been diagnosed with Parkinson's at a younger age. And so, that also means I have to go to a space that's maybe seems like for older people. But then the other pieces is just distrust of the healthcare system, healthcare professionals and research teams. I've heard examples of from a participant who was invited to participate in a clinical trial.

They invited them, gave them a set time, but they talked about they get to the healthcare facility and it's massive. And they didn't give them a map, they don't meet them down at the parking garage. So once they got parked, now they got to figure out how to get to the clinic. Where it is, ask around, navigate this, already stressed out in these pieces. By the time they finally found the clinic, they were over a half an hour late and they turned them away. So this example of just not meeting people where they are, not helping them to overcome barriers. And so, this person's like, "I'm not going to participate in research. Why am I going to donate my time for research or to benefit others when the people I'm doing this for don't even care?" And so, that's just one example of the unique challenges that we see for the community around participation in research.

Lydia Chain: Yeah, absolutely. Some of the other things that I know come to mind for people is data security. If I disclose something, am I going to be outed? Is my data secure and safe? And there's many safeguards in place to protect that kind of data when you participate in a study, but it is certainly something that gets on people's minds.

Bernard, when you're thinking about research, whether or not you participate in it, what comes to mind and what do you think needs to be studied more from our community?

Bernard Whitman: I am a researcher as well, and so I think it's so important to include all different communities just to make sure we have a representative understanding of Parkinson's in a 360 degree fashion. I think the impact of where people are in their life stage is really tremendously valuable. The more we can understand from a holistic standpoint, from a 360 degrees standpoint, gestaltian examination of the person's life, the better We are going to be able to create strategies, messaging and delivery systems to be able to bring care to people where they are.

And I think one way of doing that is just conversing with them. I think quantitative data is so incredibly valuable. We have to be able to put size behind the populations. And at the same time, I think it's critically important as well to have really engaging long form qualitative research that allows us to understand in a deep level where people are living, how they're managing and the various nuances. Because the truth is the devil always is in the details, and it's really in those spaces in between where we might miss if we're just macro looking at things. In people's homes, getting around, what's it really like, the dynamics between partners, the dynamics between families, the dynamics between doctors and patients, and how do weave all that together to really provide a clear portrait. And by the way, it's actually not a portrait, it's a series of portraits. It's a set of portraits, because just as our community is so diverse, LGBTQ, so is the

Parkinson's community. When you put those together, then you have a lot of different elements, for sure.

Lydia Chain: Yeah. What about you, Stephanie?

Stephanie Smart: Echo both what Jason, Bernard said, multiple pieces of it. And I want to tag off more of what Bernard was talking about, because we do some very similar thinking about that, is that looking at the holistic components of it, I come from complementary medicine, and so what else are people doing besides traditional western medicine? And I think we don't factor enough of that in. And so, looking at all of those pieces in addition to everything else that was talked about previously, I think what are the supplements? What are the other life activities? What are the other modalities that people are doing?

Lydia Chain: We're really looking to get a whole picture idea of someone from that macro view about the statistics, but also down into the nitty-gritty of how their real life looks and what it means to be this particular individual in their particular setup. Jase, I know that you are doing some of the research to fill these gaps. We're coming up on time here, but I'd love to hear just a little bit more about your pride study and what it's found so far, if there's any interesting findings that you can share and what's next for it?

Jason Flatt: Yeah, so Pride is Parkinson's research with inclusion, diversity and equity. And I believe it's one of the first studies to focus on the LGBTQ+ community who is living with Parkinson's disease, as well as those that are helping them with care. So it can be a caregiver or it's also, we were talking to healthcare providers that we're working at some of these centers of excellence for movement disorders.

So what's really great, we have reached about 90 LGBTQ+ people that were living with Parkinson's disease, and we also reached about 120 non-LGBTQ+ people living with Parkinson's. We really focused on diversity in terms of backgrounds. So race, ethnicity, age, gender, identity, you name it. We also, Bernard brought up that important point around qualitative research. So we did some qualitative interviews with 13 caregivers of LGBTQ+ people living with Parkinson's disease to really get at in depth what are the unique experiences. And then we talked with over 100 healthcare providers around their preparedness and some of the unique needs of supporting the community.

So some of the things that stood out to us, really, they focus on things like we do see greater needs for the LGBTQ+ community living with Parkinson's. So some of the areas around, I mentioned before, mental health, right? So we're finding some concerns around higher rates of anxiety. We're also seeing some challenges around care. So things like experiencing discrimination, being denied care, having to teach their provider, and also having broader mistrust of the care.

In terms of the caregivers, I've shared a little bit there is a lot of reward from the caregiving, but there's also an area of need. So not having access to care that's truly welcoming. Caregivers talking about we need more support, we need the ability to focus on our own health. We need to address something they talked a lot about is like advocacy. We need more support groups, we need more services for those that are helping with care, but also for the people living with Parkinson's.

And then for providers, the main pieces that we saw is just some strengths around, yes, there is some representation, there is some inclusion, for instance of same-sex couples, some collection of gender identity and some policies around protection at these institutions, but not a lot of training and not a lot of knowledge about the unique needs of LGBTQ+ people living with Parkinson's. So my hope is that some of this can increase inclusion in research. My big concern that I've heard is people not being included in clinical trials and some of these unique barriers. And so, that's another area that I hope that we can encourage more work to happen.

Lydia Chain: Well, we'll be looking forward to even more of your findings. Thank you so much for sharing them with us, Stephanie and Bernard, I'm going to give it to you for the last word here. Is there something that you would like to communicate to your community? Bernard, you start.

Bernard Whitman: The power of music. I have spent much of the last two and a half years, oftentimes immobile, really very, very terrible gait freeze and so forth. Music has unlocked my movement repeatedly. And in the spirit of pride, we have so much identification with music. I encourage everyone out there when they're feeling whether it's down, immobile, frozen, mean, virginity, stiffness, put on your favorite track of old, of new, doesn't matter what. And if that one doesn't work, go to the next and go to the next, go to the next and go to the next. And I guarantee you sooner rather than later, you'll hit on some song and you'll get up and you'll start dancing, and that will unlock your brain. So use music. It works.

Lydia Chain: Beautiful, beautiful. Stephanie, what about you? What's your advice? What do you think the community needs to hear?

Stephanie Smart: Well, now I have to think of something else. I think one of the things that we talked about earlier, or Jason mentioned, was the mental component of Parkinson's. And there's a component of being alone and being lonely and not taking advantage of resources. And two of the things that have really been so important for me is being in support groups with other LGBTQ members of this community. And it has been so beneficial to not be the only one in an environment and to be included, and to have Parkinson's be the discussion versus am I going to have to come out? Am I going to have to do all of that component?

And so, really take advantage of the resources that are available for our community. And if there isn't a group, if there isn't a support group, if there aren't other people, figure out how to make that happen. Figure out how to reach out to people and take advantage of that, because it is so important for your mental health and the progression in your own self-care in this disease.

Lydia Chain: I want to thank all of you for joining me on this episode today. It was really wonderful having you.

Bernard Whitman: It was so great to be here. Happy pride, everyone.

Lydia Chain: Thank you.

Jason Flatt: Thanks for having us

Lydia Chain: To connect with other people living with Parkinson's, including those who are in the LGBTQ+ community. I really recommend the Parkinson's Buddy Network. It is a great place to find people in a similar position as you. There'll be a link in the show notes. Please rate and review our podcast. It helps listeners like you find our show. I'm your guest host, Lydia Chain. Thank you for tuning in.

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