

Episode 110: Social Isolation and Loneliness

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Dan Keller: Welcome to this episode of *Substantial Matters: Life and Science of Parkinson's*. I'm your host, Dan Keller. At the Parkinson's Foundation, we want all people with Parkinson's and their families to get the care and support they need. Better care starts with better research and leads to better lives. In this podcast series, we highlight the fruits of that research, the treatments, and techniques that can help you live a better life now, as well as research that can bring a better tomorrow. Social isolation and loneliness are risk factors for poor health outcomes and mortality. Possible contributors to social isolation are mobility problems, diminished hearing, or vision, anxiety, depression, apathy, fatigue, and loss of loved ones. They occur in the general population and can particularly affect people with Parkinson's.

However, not much research has been done in this area, prompting Dr. Indu Subramanian, of the West Los Angeles Veterans Affairs Medical Center, to conduct a survey among people with Parkinson's disease to investigate the association of social isolation with symptom severity and quality of life. She performed the survey prior to the COVID-19 pandemic, which made social isolation somewhat of the norm for many of us. In this episode, she discusses the findings of the survey and offers some ways that people may become more socially engaged.

Dr. Indu Subramanian: We looked at things that were beneficial for these patients in terms of their quality of life. Then we looked at things that were detrimental, and we noticed that actually, loneliness was very detrimental to their health, and the types of things that were positive included exercise. The loneliness factor in these patients was as bad for patients to be lonely as beneficial effects of exercising seven days a week for 30 minutes a day was good for them.

Dan: Do social isolation and loneliness affect people with Parkinson's in particular or more severely than other people of similar ages?

Indu: Yes, I think the Parkinson's population is specifically at risk for this problem. Many of our patients do have some sense of a stigma with carrying the diagnosis. They have some motor issues like feeling immobile, sometimes they may have tremor that might be embarrassing, might be embarrassed by dyskinesia, some of the extra movements that they get. May not go out of the home or be in social circumstances as much as people that are age-matched, then you add on the non-motor issues that our Parkinson's patients get. That is really something that can affect their ability to leave their homes and connect with other people. We have apathy, we have things like depression and anxiety, we have fatigue, a lot of these things can affect patients and their motivation to get involved in leaving their home and connecting with other people.

Dan: Loneliness is really a feeling or a perception. How do you define loneliness? What domains does it fall into or contribute to it?

Indu: That's a good question. We look at social isolation, which is something that's a little bit more measurable. We can see how many people a person may live around, we might be able to see who they interact with and you can measure these things. Loneliness is really this subjective feeling. What I've grown to understand is that there's this sense that you want certain types of relationships, you want certain types of qualities and relationships, and those may be different than the ones that you actually possess. There's this gap between the relationships that you have and the relationships that you want that really defines this lonely feeling. The other thing that was interesting is that I had always had the perception if somebody was married if they were happily married living in a home with somebody who cared about them, there was no way that they could be lonely. I didn't have to ask about that.

Actually what I learned through some of the research was that you actually have to have three spheres of connection in order to feel connected to people. There's this intimate sphere of connection in which you feel connected to perhaps a spouse. Then there's a second sphere in which you have friends, have circle of friends that can have this relational connection. Then a third sphere, which is more of a societal sphere which you have a connection of community, maybe through something like alike purpose alike interest. I take care of veterans, a lot of veterans feel connected to the VA and other veterans, women who are moms might be connected to similar types of people. I think everyone has the need to feel connected in these three ways. One can ask about these things specifically to help to understand who may actually be lonely.

Dan: Why are people with Parkinson's particularly at risk for being lonely?

Indu: The problem becomes that there's this self-fulfilling prophecy. You have patients who may be already withdrawing from society. Loneliness itself can affect health in general, significantly. We know from other research and other areas, loneliness can cause increased morbidity and mortality. It's as bad for you to be lonely as smoking a half a pack of cigarettes a day or being obese. There's also research that shows that loneliness can affect stress. It increases stress. It can affect sleep cycles, it can affect immunity, it can affect cognition. The way that it affects cognition is pretty profoundly. People who are lonely when you examine them, they tend to fixate on more negative stimuli, they tend to get quite ruminating on things over and over, and sometimes they become paranoid if loneliness is left unchecked.

When we think about a Parkinson's patient, we have patients who may at baseline feel disconnected because of what we've talked about. They may have a stigma, they may have motor and non-motor issues that cause them not to want to connect with other people. Then we add on the effects of loneliness which can affect their cognition, their sleep. It can cause them to think bad thoughts, focus on negative stimuli, increase stress, and this can then impact other issues like their motor issues. It can affect their non-motor issues. Then it can be a bad cycle in which patients who are already at risk end up getting worse and worse. They then withdraw more and more and can really get derailed with some of their mental state, their cognition, their motor function, and non-motor function.

Really it's a population that's already at risk and we saw this data going into the pandemic. Then we add on the pandemic of COVID with its restrictions on social

distancing and sheltering in place. This has really made us worry about this already at-risk population.

Dan: You published this study in nature Parkinson's journal, and you looked at a lot of symptoms and quality of life and other measures related to isolation and loneliness, but you really didn't have a control group. These were people you were following. Is it possible that it's a case of reverse causality that some of these symptoms that limit their social interaction are causing the loneliness as opposed to loneliness causing an exacerbation of symptoms?

Indu: I think that's a really good question. That is one of the downsides of doing this type of survey. We have some data from non-Parkinson's patients on the effects of loneliness and we see that this is something that can affect various measures of health. This has been seen in animal models and various types of age groups, isolated medical students and tests, and even aging populations. We do know that loneliness affects health. You're absolutely right though that we can't tell in Parkinson's population if what's caused and what's effect. We know that these things live together and that they can compound each other.

We have a figure in the data that is showing information about non-motor symptoms, and it really shows that there are a number of non-motor symptoms that seem to associate with being lonely and these things are things that you would predict would also compound the loneliness. Things like fatigue, things like poor sleep, things like anxiety, depression. We can't really say what's cause and what's effect. We know that, and these things live together. Our conclusions do describe that these sorts of issues as compounding variables possibly. I think when we approach the data set and what we could proactively do, I think that many of the interventions that we would talk about could actually help both.

We were talking about ways that we can keep people engaged through proactive ways in social prescribing, trying to help them connect with people. We're trying to help them keep their wellness strategies in check. We're trying to keep them exercising, keep them doing mind-body approaches, keep them doing many of the things that would help their motor and non-motor symptoms anyways. We're really just trying to increase awareness of this issue with neurologists who are treating Parkinson's patients and not just neurologists, but really anyone who may be able to impact the day-to-day care of our patients.

It might be the clerk that checks my patients in at the front desk at the VA who might be able to have a chat and try to connect the patient with a resource. At the VA, we actually have a new social prescribing intervention. What they've done is they've taken people of volunteers that used to physically come into the VA and those volunteers were told to not come physically into the VA and have been missing their own volunteerism, and the benefits from that, they redeployed this volunteer force and have been soliciting new volunteers, which has gone very well actually. What they're doing is trying to match volunteers with like-minded or like-interested lonely patients and really have them connect either through digital modalities such as an iPad, or maybe just old school phone calls because many of our patients are actually at risk for not having technology, or not being technologically savvy, perhaps not having the funds to have good Wi-Fi, or a computer, or a smartphone and really are being left out of the current modalities of telehealth, or other proactive strategies to

outreach if you're using a virtual support group, for example, or other things that require being able to operate a computer.

Really, this is getting a very simple strategy for proactive phone calls to lonely patients. I think that we'll see what the benefits are but I am really excited because it can possibly have benefits not just in the patients themselves but even in the volunteers as well.

Dan: From what you describe, it sounds like clinicians have to intuit that this person may be lonely, whether it's the person checking them in, or a nurse practitioner, or a movement disorder specialist. Are there actually any questionnaires or tools that could reveal this more directly? I guess the ultimate question is, how aware are physicians of the need to detect loneliness?

Indu: What we know in loneliness is actually that loneliness is a pretty high-risk factor in many populations, and especially veterans, for suicide. The VA has actually taken this quite seriously. You asked about questionnaires, actually, one of the questionnaires is the questionnaire that comes out of UCLA. There's a number of questions, I think it's about a 10 question questionnaire in its totality, maybe 10 to 12. I think you can take three questions out of that and actually have some yield and so we're able to use these three questions to surveil patients. My hope is to incorporate this, possibly, into the charts, the medical record, and have patients be identified. It may not be that it's me as the movement disorder provider with the white coat. It might be their primary care doctor, it might be a social worker, it might be clerks or somebody else that can proactively reach out.

I think it's very powerful time frame that we're in that hopefully we can take these things a little bit more seriously and put in the resources for care that have probably been needed for a long time.

Dan: If a person with Parkinson's does feel lonely, what can they do now?

Indu: I think one of the things we really know is that patients aren't going to come to us and complain about it, that's not something that is part and parcel, something that they would think should be talked about to a neurologist. The truth is-- I think Dr Murthy, Vivek Murthy, who is our current Surgeon General of the United States, has done some amazing work.

He wrote a book called *Together* and he's really highlighted, with some of his own anecdotes about his own life and his own loneliness through middle school and high school, about the effects of this on himself. He talks about loneliness as a societal pandemic. This was a book that was written even before the current COVID-19 pandemic. It's really shone a light on the problems with expecting people to realize that this is a problem and complain about it.

The truth is that being lonely is associated also with a stigma. You feel if you don't have people in your life that care about you, you don't have these relationships that probably you didn't deserve these relationships. Maybe there's something unlikeable about you and that's why you're lonely. A lot of people are embarrassed about this. They may not come forward. I think we have to normalize this conversation and

normalize the attention to this as part of the holistic approach to patients with not just Parkinson's disease, but health in general.

I would hope that one could think about social connection as a basic nutrient, just like food, and water, and sunlight, and shelter. I think this is something that we need as human beings and I think so much of our lives have gone away from this before. I think the pandemic has been a time when we've been able to reflect a little bit more on how important this is for human functioning.

Dan: What have we missed, or maybe nothing?

Indu: I think that we have, again, an opportunity. I have done some talking, I ended up, actually, getting a TED Talk invite within the VA system, to talk about loneliness. I think people realize that this is something that is necessary to highlight. I think these things can be very powerful. We're all human. Even if I'm wearing a white coat, all of these things can affect me just as they can affect you, as can affect my patients and even their caregivers.

I usually end these talks by saying, "Think about how you can affect change in your own community," perhaps connecting more with your neighbors, connecting more with the people that might have been forgotten. Somebody may be living up the street that lives alone, that doesn't have anyone to check in on them. Maybe drop them a note, leave your phone number, have a phone call. Maybe reach out to somebody on your Christmas card list that you've forgotten about since high school.

I, myself, have done some of that, during this pandemic time. I think it's really been an amazing way to connect with people. Really, it's been a silver lining. I think if you can make a change in your behavior, maybe reach out to somebody proactively, you may save somebody's life, you just never know. It's pretty amazing. Think outside that box, I think there's a lot of teenagers that are around that are possibly helping schedule vaccination appointments for patients right now, that might have come out of the woodwork in their communities.

Perhaps we can continue the dialogue, with having teenagers that could be checking in on elderly. I know my oldest child is quite connected as the IT help desk support to his grandparents, who live in Canada right now. It's part of their weekly check-in with their grandson, get all their devices fixed up, and also, he gets to check in on them. I think it could be a beautiful thing.

Dan: Very good, thanks for all the practical information. I'm sure it's going to come in useful for both clinicians and people with Parkinson's.

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Dan: In a publication on the survey, Dr. Subramanian suggested that health care providers be aware that some patients may feel lonely even when surrounded by people, sometimes called lonely in a crowd. On the other hand, some introverted people may prefer not to have others around them and report no issues with feeling lonely. For individuals who feel lonely and are unable to influence their social conditions, the situation may be especially stressful.

One new concept is social prescribing, where clinicians recommend community resources or activities to help people find and develop healthy social connections. Such resources may provide home visits or phone calls on a regular basis or connect people to social programs in the community. These sorts of programs may increase interactions and diminish loneliness for both the recipients of the resources and for anyone volunteering at them, for example, to make the calls.

Resources and programs may include exercise or art classes, volunteer opportunities, self-help groups, and activities such as gardening, cooking, or other hobbies. All these activities in themselves may be beneficial but more work still needs to be done to see if relieving social isolation slows the progression of Parkinson's. For more on the subject, search our website at parkinson.org, for loneliness, and for social isolation. There are also past podcasts, titled *Mental Health in a Medical Setting*. Two on mindfulness in PD, and another on tai chi exercise. You can also engage with us weekly through our educational and wellness PD Health at Home programs, by visiting parkinson.org/PDhealth.

If you have questions about this topic or anything else having to do with Parkinson's, our information specialists can provide answers in English or Spanish. You can reach them at 1-800-4PD-INFO.

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