



Transcript

Welcome and Introductions

Rebecca Gilbert, MD, PhD

[Slide 1] Thank you so much. Welcome everyone and thank you for joining us today. **[Slide 2]** My name is Rebecca Gilbert, and I am APDA's (American Parkinson Disease Association) Vice President and Chief Scientific Officer.

I'm pleased to welcome you to this Web/teleconference education program designed for people with Parkinson's disease as well as their care partners, family members, and healthcare providers. I would like to thank Acadia for funding this important program and acknowledge their appreciation for the critical need to provide educational programs like this one to people impacted by Parkinson's disease.

During this time of uncertainty, we know that you still have concerns regarding your Parkinson's treatment as well as identifying ways to continue to live your best life with PD.

American Parkinson Disease Association or APDA for short is the largest grassroots network dedicated to fighting Parkinson's disease and works tirelessly to assist the approximately 1 million Americans with Parkinson's disease. APDA distinguishes itself as the national organization working one on one with the Parkinson's community to make each day better. And now to our program.

[Slide 3] Our presenter today is Dr. Cristina Colón-Semenza, Assistant Professor, Doctor of Physical Therapy program at the University of Connecticut. Today we are delighted to have Dr. Colón-Semenza share with us information to help you keep your body and mind healthy.

After the presentation, we will open the program for questions from both telephone and Web participants. We encourage everyone on the line to complete the evaluation after the program because your feedback is instrumental in helping us plan for future educational offerings, including teleconferences like this and other programs.

It is now my pleasure to turn the presentation over to Dr. Colón-Semenza.



Presentation

Cristina Colón-Semenza, PT, MPT, PhD

[Slide 4] Thank you, Dr. Gilbert, for the introduction. And thank you APDA for inviting me to speak to you all today. My name is Cristina Colón-Semenza. I'm a physical therapist and an Assistant Professor at the University of Connecticut. And these are my financial disclosures.

[Slide 5] We're going to be talking about what is social support, what do we know about social support and exercise? How can it help me to stay healthy and manage my Parkinson's disease, and how can I benefit from this, especially now while social distancing during the COVID-19 (coronavirus disease 2019) pandemic?

[Slide 6] So, I start off with a little bit of inspiration by a British poet, William Blake, that very eloquently said, "The bird a nest, the spider a web," and I'll change it a bit here to say, "human friendship." So, this is just to orient us that the same way the bird finds its home in the nest, the spider finds its home in the web, humans find their home in the social world. We are social creatures, born into a social group, and shaped by the society that we live in. So, it's argued that socialization has moved our society forward, and it is what helps to keep us well and healthy.

[Slide 7] But what is social support? I think most individuals think of it simply as friendship, and that is one component of it. Companionship, that individual who you can go on a walk with or share some of your challenges and joys. But it's also emotional and informational. So, it's that person who you can rely on when you are needing a shoulder to cry on, or you need someone to share in your joy for overcoming a challenge that you just accomplished, or it could be that person who maybe you met in a support group and told you, "Hey, have you seen this website? It has great information about diet, or have you read this great book? It gave me really great information on medical management in Parkinson's disease." It can also be tangible support, which are providing things like financial resources or housing. But today we're going to be focusing on these top three – informational, companionship, and emotional.

[Slide 8] So, social support can come from, like we've mentioned, friends, family members. It can even come from pets. It can come from your grandchildren, your neighbors, but it might even come from individuals who are also living with Parkinson's disease and sharing some of the similar challenges and achievements that you might be sharing.

[Slide 9] The flip side of that coin is social isolation, which a lot of individuals might be experiencing now during the COVID-19 pandemic. We know that in older individuals who are socially isolated, they have higher levels of all-cause mortality, higher levels of cardiovascular disease and worse mental health. **[Slide 10]** But the positive side of that coin is that when there is social support, we see improvements in mood, reduced depression. There is improved cognition and memory, improved quality of life allowing you to engage in the activities that you enjoy and value, improved longevity. There are studies that are done that look at super agers, these individuals who are living well into their 90s or their 100s and having great quality of life. And we find that those individuals have strong



social support networks that they're sharing with these individuals – their challenges, their stressors, and their joys.

And then related to that, we find that those individuals who have social support also have higher physical activity levels. **[Slide 11]** And I'm sure you've heard this message lots before. We know that exercise is beneficial for everyone, but especially exercise seems to have this power in the management of Parkinson's disease. We see that exercise improves strength allowing you to get up from that low couch or out of your car seat, allowing you to have improved balance improving your heart and your lung fitness, allowing you to get around your home or in your communities and function and maintain independence and quality of life. And what is maybe the most exciting finding is that there is even some evidence to say in animal studies and in clinical trials that exercise might even slow disease progression when measured by the Unified Parkinson's Disease Rating Scale (UPDRS) looking at our motor symptoms. So, this is some pretty exciting power that exercise holds in the management of the disease.

[Slide 12] So, what happens when we take these two really powerful interventions and tools, social support and exercise, and bring them together? How do they interact? Well, there's one study that looked at what helped individuals to actually stay and adhere to their exercise, right. It's one thing to start exercise, it's another thing to sustain it. This is a challenge for everyone. It might be a little bit more challenging when you're living with Parkinson's disease. But one study found that a group exercise program provided such a nurturing environment, and this social cohesion which was one of the most important features that the group members identified as being important for them sticking with their exercise.

So, you might be saying, "Great, Cristina, I did that before. I had a boxing class or a dance class that I used to attend, but now because of the COVID-19 pandemic and social distancing, I can no longer do that." **[Slide 13]** So, you might be asking, "Now what? How do I maintain the benefits from exercise and social support and stay safe during the COVID-19 pandemic?" Well I will say, I'm not the first to say it, but I will restate here that social distancing is a bit of a misnomer. We can still be socially connected and be physically distant from one another. So, maybe it's physically distancing so that you can still have that social connection and still benefit from all of those amazing things that social support provides us for our health and our wellness.

[Slide 14] There are actually some studies that have done this. These studies were done before the COVID-19 pandemic, but we can learn from them because the way that individuals connected in these studies was all remote or virtual. So, in this one study by Liu & Lachman, they took older individuals and one group just was given an activity tracker. The other group was given the activity tracker, but then they had a whole group of individuals also connect by sharing their walking activity and by texting each other just checking in saying, "Hey, guess what, I walked 10,000 steps today." Or "Oh, today was a hard day for me. I didn't get out the way I wanted to because it was raining." And those individuals who had that social connection just simply by texting and sharing their walking information, those individuals had significantly greater increases in their walking per day and they also felt more socially supported. The individuals in the control group did not have this increase in physical activity. So, again, here's an example of staying physically apart but still socially connected.



[Slide 15] Here's an example where individuals with Parkinson's disease had an in-person tango group and a virtual tango group. So, the curriculum was exactly the same, but in one group, the instructor was in a remote location. And they found out that in both groups they adhered to the exercise program, they enjoyed it, they stuck with it and there were no adverse events so there were no problems or falls during this study and the both groups ended up having similar outcomes. So, improvement in balance and improvements in their motor symptoms, so their tremor, rigidity and their slowness of movement.

[Slide 16] And then the final study that I'd just like to share with you all is one that I was involved with at Boston University. And in this study, we connected individuals with Parkinson's disease. One group were individuals who were striving to be more physically active but weren't yet at their goal for physical activity. The other group, who we called peer coaches, those individuals had already achieved their goals of being physically active, so they served as the peer coach. So, both groups of individuals received Fitbit Zips, and they became Fitbit friends on the Fitbit activity tracker so they could, again, see each other's physical activity that was accumulated over the week. Individuals spoke to each other over the phone once a week for eight weeks. So, again, this whole interaction was all virtual, nothing in person.

[Slide 17] And what did we find? We found that individuals on average had a 31% increase in their steps per day and an over 40% increase in their active minutes per week. So, again, this was completely virtual, so they were staying physically distant, but they were socially connected, and they supported each other's physical activity. **[Slide 18]** So, if you are looking for some connection, some social support and looking for some ways to be more physically active, the APDA can be a great resource to you providing virtual exercise classes as well as virtual support groups.

[Slide 19] And I'll leave you with a bit of inspiration that anything is possible when you have the right people there to support you. **[Slide 20]** So, social support and exercise, both independently and together, can enhance your physical and mental health, and you can still safely and effectively benefit from social support and exercise during this challenging time of the COVID-19 pandemic. Thank you so much for listening.

[Slide 21 and 22]

Rebecca Gilbert, MD, PhD

Thank you so much, Dr. Colón-Semenza, for an extremely insightful presentation today.



Question & Answer

Rebecca Gilbert, MD, PhD

[Slide 23] It is now time for our Question & Answer session.

We're already having lots of questions come in through the web, and so let's get started. We have a great question here from Dan, which is, "Do you have any suggestions for those with late state Parkinson's who may have frequent falls to help maintain an overall level of activity?"

Cristina Colón-Semenza, PT, MPT, PhD

Thank you for that question, Dan. Yes, so that is a common question that we get. And so, the positive side of that is that we have lots of evidence to indicate that aerobic exercise is specifically powerful in the management of Parkinson's disease. So, that if that individual is having difficulties in the standing position being safe and maintaining their balance, there are lots of ways to get seated aerobic activity. So, for example, doing a recumbent bike or a seated cross trainer, which you can have your arms and legs going, that is an exercise that can get your heart rate up, increase your respirations, you will get all those benefits of cardiorespiratory fitness and exercise and engagement and help to garner some of the benefits that exercise can provide in Parkinson's disease. Additionally, there are some exercise programs that can be done from a chair. So, seated yoga, seated exercise programs specifically for people with Parkinson's disease and so those can be beneficial as well.

What I will indicate is that what we know and what seems to be a commonality in the evidence for exercise for people with Parkinson's disease is that in order to garner the benefits, it needs to be progressive. So, as long as someone is constantly challenging themselves, is working to their capacity, we will see benefits that are seen, but there should always be a challenge that is incorporated into that exercise program.

Rebecca Gilbert, MD, PhD

Fantastic, thank you. Here's a wonderful question that many, many people ask, which is, "If you have an hour exercise session, should I be varying my exercise or should I do more repetitive exercises again and again, or should I do a variety of things?"

Cristina Colón-Semenza, PT, MPT, PhD

So, that is a great question. Thank you. So, yes, this can be challenging when there are so many recommendations out there. But you can think of the recommendations for exercise and physical activity being in three buckets. So, we get our recommendations from the American College of Sports Medicine (ACSM) and Health and Human Services (HHS) that advocate for us achieving 150 minutes of moderate to vigorous physical activity over the course of the week. So, that can be broken down in a variety of ways, so it can be 30 minutes five days a week or it could be ten minutes over six days of the week. So, you can achieve that in small bits or larger bits, whatever works for your needs. But in addition, the recommendation says that we should be getting two days per week of strength training and two days a week of balance training.



So that might sound like a whole lot, and you're thinking, my goodness Cristina, I can't do all of these things. Well there are certain exercises that allow you to check off more than one of these buckets. So, for example, a dance class, in this dance class if you're dancing for 30 minutes and you're feeling that your heart rate is up and you're getting a little sweaty and you're breathing a little heavy, well that is achieving that 30 minutes of aerobic activity, that moderate to vigorous aerobic activity. But it is also likely achieving that bucket of balance training. So, there are lots of different ways where you can kind of double dip and check off two boxes simultaneously. So, that hour can be put together in lots of different ways to meet your needs. But I also will say, "Make sure that what it is that you're doing is enjoyable. It is something that you want to return to and continue with because this is something we know that needs to be sustained to maximize the benefits."

Rebecca Gilbert, MD, PhD

Fantastic. Thank you so much. And we now have a question that we've gotten in a variety of forms. "Are there specific exercises that help with some of the nonmotor symptoms of Parkinson's Disease?"

Cristina Colón-Semenza, PT, MPT, PhD

That is a great question. So, yes, we do have evidence that, actually there's strong evidence for group exercise classes reducing both depression and improving cognition. We also have evidence that group exercise reduces anxiety and improves sleep. I will make note that all of these studies that improved these nonmotor symptoms all included some component of deep breathing and relaxation, so, for example, things like yoga. There is also evidence that aerobic exercise, so cycling, fast walking, things that just elevate your heart rate and your breathing, those too have evidence for improving sleep, depression and improving cognition, so your memory and thinking, things like this. So, yes, there is strong evidence that exercise can improve the nonmotor symptoms in PD.

Rebecca Gilbert, MD, PhD

Fantastic. A related question, "Is it helpful to do things other than physical exercise to help with cognition and Parkinson's disease? Things like puzzles or words games; any evidence that people should pursue that?"

Cristina Colón-Semenza, PT, MPT, PhD

Yeah. So, there is evidence of benefit for exercises for your brain, but what we're finding is that, unfortunately, if you're doing puzzles to exercise your brain, you improve your skills at puzzles. We don't find a transference of skill so that individuals who are doing better with puzzles then have better working memory to be able to carry out functions in their day-to-day lives. So, it's beneficial in some regards that you can build a skill, but, unfortunately, we're not finding the translation of those skills into everyday function.



Rebecca Gilbert, MD, PhD

Great. Thank you. Here's another question. "Can you comment on the specific PD exercise program LSVT (Lee Silverman Voice Treatment) BIG and LSVT LOUD? Are those programs that you recommend for your Parkinson's patients?"

Cristina Colón-Semenza, PT, MPT, PhD

So, yes. Thank you for that question. I know the LSVT BIG and LOUD are very popular across the US, and there is a ton of evidence for LSVT LOUD. There's less evidence for the efficacy of LSVT BIG. What we do have a ton of evidence for, an overwhelming amount of evidence, is for aerobic exercise, balance exercise, and strengthening exercise. So, those three components are often a part of the LSVT BIG program. But what we have the strongest amount of evidence for are those three buckets that I mentioned – aerobic exercise, strengthening exercise, and balance exercise. So as long as you're hitting on those buckets, it doesn't necessarily have to be packaged one particular way so that you can work with a physical therapist to make a program that is just right for you and for your needs. It doesn't have to be one specific program because we have not found that one specific program is actually better than the other. There have been a couple of studies that have compared different types of packages and programs, and we're not finding that evidence to say definitively, "This is the one that you have to do." So, just focus on getting those three buckets – aerobics, strengthening, and balance – into your physical activity program and plan.

Rebecca Gilbert, MD, PhD

Excellent, thank you. So, now another question "Are there ways using exercise to decrease my chance of developing dementia in the future? So, now I don't have any cognitive issues. Will exercise prevent my developing dementia?"

Cristina Colón-Semenza, PT, MPT, PhD

Yeah, that's a great question. So, actually, the good news is that there is evidence for both of those things that I talked about today, both social support and exercise, reducing the risk of cognitive decline. So, it might not completely prevent it, but it can reduce your risk. So, starting an exercise program and finding that support group to join or getting the support from your family, your religious group, wherever you find your support and your comfort, your companionship, your information, your emotional support, all of those things are steps that you can take right now to minimize your risk of dementia.

Rebecca Gilbert, MD, PhD

Fantastic. And with that, we have come to the end of our time. It passed so quickly.



Closing Remarks

Rebecca Gilbert, MD, PhD

[Slide 24] So, I want to thank you very much, Dr. Colón-Semenza for joining us today and my many thanks to everyone participating in today's telephone and web education program. I really apologize we couldn't get to all of our wonderful questions. As you heard, there were so many really excellent questions, and I hope people got some great information. **[Slide 25]** If you have an additional question or would like to speak to someone from our Scientific and Medical Affairs Department, I encourage you to visit our website at apdaparkinson.org or call 1-800-223-2732, and you can ask your question there.

[Slide 26] If you enjoyed today's webinar, we hope you will consider supporting APDA with a donation. And with your help, APDA can deliver more programs and services like this one, which are needed now more than ever during these challenging times. **[Slide 27]** And remember to check out the APDA Symptom Tracker, which is an app that helps you or your loved one track their PD symptoms. The symptom tracker is available in English and Spanish and can be downloaded from the App Store or Google Play.

I want to emphasize to everyone, including those on the phone, that we really do appreciate your feedback and comments and want to make sure that you complete the program evaluation form. To join us in this fight against Parkinson's and to learn more about the support APDA provides across the country through our network of chapters and informational referral centers, as well as our research grant program and centers for advanced research, please visit us at apdaparkinson.org. We all agree that being informed about your disease and treatment options is the best way to empower yourself and take control of your care. Have a wonderful day.