TITLE: Promoting Physical Activity via Telehealth in People With Parkinson Disease: The Path Forward After the COVID-19 Pandemic?

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Objective. There is mounting evidence in support of exercise and physical activity as a first-line approach to managing symptoms and potentially altering disease progression in people with Parkinson disease (PD). For many patients, a critical gap is the need for expert guidance to overcome barriers, set realistic goals, and provide personalized advice to optimize exercise uptake and adherence. The purpose of this case report is to describe a physical activity coaching program for individuals newly diagnosed with PD

(Engage-PD) and to highlight rapid modifications made to this program in response to the COVID-19 pandemic.

Methods (Case Description). Engage-PD is a single cohort implementation study of a coaching intervention grounded in self-determination theory being conducted at Columbia University Parkinson's Foundation Center of Excellence in New York City, the early epicenter of the COVID-19 pandemic in the United States. The project was uniquely positioned to be adapted to telehealth delivery and to address an immediate need for support and guidance in the home environment, including people with early-mid stage PD. Participants completed baseline and follow up (3 months) assessments, and participated in up to four coaching sessions all delivered via telehealth platform. The intervention incorporated 1:1 coaching, goal-setting, physical activity monitoring, and use of a disease-specific workbook to promote and support safe exercise uptake.

Results. While the program is ongoing, 52 referrals were reicieved and 27 individuals enrolled with PD in the first 2 months of the pandemic for a recruitment rate of 52%. Although direct comparisons with pre-coronavirus recruitment are difficult due to the recency of the Engage-PD implementation study, this recruitment rate was larger than expected, which may have been due to several factors (eg, most patients had limited, if any, access to in-person programs and therapy services during this time, so the Engage program filled an immediate need to provide exercise and activity guidance). There was a wide range of scores for both baseline physical activity and self-efficacy measures.

Conclusion. Remotely-delivered interventions may serve as a sustainable platform for physical activity coaching programs for people with PD as well as other neurodegenerative diseases.

Impact. With the uncertainty brought about by the current pandemic, this case report highlights the opportunity to shift the current model of care for individuals with neurodegenerative diseases such as PD.

The benefits of exercise for people with Parkinson disease (PwPD) are well known, with a wealth of community-based interventions offered for the over 1 million individuals living with Parkinson Disease (PD) in the U.S.[1] Community-based programs provide PwPD invaluable access to low-cost programs and are an essential complementary treatment to individualized physical therapy that may be limited by geographical constraints, service restrictions, or insurance stipulations. Importantly, physical therapists should play a role in facilitating exercise uptake in the community, and therapist-delivered coaching programs to promote PwPD to engage in exercise, particularly soon after diagnosis, are lacking.[2] In particular, there is a need for interventions that facilitate enhanced self-efficacy for physical activity engagement,[2,3] while specifically addressing barriers and facilitators unique to each individual.[4,5]

There is also growing evidence in support of the neuroprotective benefits of aerobic exercise in individuals with neurologic diseases and disorders.[6–9] However, PwPD have specific barriers to exercise uptake, including disease-specific balance and gait impairments, apathy and depression that may result in a greater likelihood of sedentary behavior.[5,10] In addition to high levels of sedentary behavior, PwPD are frequently referred to rehabilitation services once the onset of disability occurs, wherein progressive mobility, activities of daily living, and cognitive declines can lead to a rapid deterioration in functional status, increased risk for falls, and subsequent rates of higher healthcare utilization.[11] Early referral and implementation of exercise

and coaching programs are needed so that individuals may capitalize on the benefits throughout the course of their disease.

The purpose of this paper is to describe a physical activity coaching program for individuals newly diagnosed with Parkinson disease, *Engage-PD*, and to highlight rapid modifications made to this program in response to the coronavirus pandemic. While modifications to the *Engage* program were made to adapt to stay-at-home guidelines, we discuss the importance of remotely delivered interventions as a sustainable platform for future physical activity coaching programs for people with PD.

[H1] Physical activity coaching and the Engage-PD program

Physical activity coaching programs have been developed over the past several decades to combat sedentary behavior and address barriers to exercise uptake. Programs such as the LIFE program for neurologic disorders in the UK[12] and ParkFIT for PD in the Netherlands[3,13] have used similar models of behavioral change interventions to facilitate physical activity uptake and adherence. Key components of such programs include disease-specific education, personalized coaching by trained professionals, and individualized goal-setting. It is important that such programs be implemented at the earliest stages of PD, where identification of exercise habits and barriers can be addressed.[14]

At the Columbia University Parkinson's Foundation Center of Excellence, we developed a program to deliver physical activity coaching for those who are newly diagnosed and/or are in the earlier stages of PD using the *Engage-PD* program (Columbia University Irving Medical Center IRB# AAAS4709). *Engage-PD* is a single cohort, implementation study of a coaching intervention originally designed for persons with Huntington's disease,[15] which has been adapted

for individuals with PD.[16] This program provides individuals with the tools needed for secondary prevention of physical activity decline throughout their disease course, with particular emphasis on individuals newly diagnosed and in the early disease stages. The Figure illustrates the *Engage-PD* logic model, including inputs (coaching sessions, disease-specific workbook and educational components, and physical activity monitoring) and outputs (assessments and impact).

Prior to the pandemic restrictions, neurologists referred study candidates during clinic hours at Columbia University Irving Medical Center, so they could readily participate in the *Engage-PD* program on the same day as neurology appointments within our multi-disciplinary center. Participants were screened for readiness to engage in exercise using the Physical Activity Readiness Questionnaire (PAR-Q).[17] Baseline measures included the Timed Up and Go (TUG), 10m walk test (10mWT), 30 second chair stand test (30sCST), Brunel Lifestyle Physical Activity Questionnaire,[18] and the Norman Self-Efficacy Scale.[19] Participants received one in-person and one remotely-delivered coaching session, followed by a follow-up remote assessment at three months.

The *Engage-PD* intervention is grounded in self-determination theory,[20] promoting individual autonomy, competence and relatedness. *Engage-PD* is designed to address barriers to exercise engagement and support adherence to individualized exercise plans that are both purposeful and meaningful to patients. The program specifically targets those individuals who are not currently engaged in sufficiently intense or frequent levels of exercise, empowering them early in the disease process with adequate knowledge and self-management techniques through a coaching program. By using a behavior-change model, *Engage-PD* promotes self-efficacy and

regulation of motivation for exercise, thereby facilitating long-term sustainability in each participant.[21] A disease-specific workbook, which was developed after piloting in a previous study,[16] includes evidence-based exercise recommendations including frequency, intensity, and duration for aerobic, strengthening/resistance, flexibility and neuromotor exercises.[22,23] This includes recommendations to incorporate high intensity aerobic exercise a minimum of three times per week, however this advice is individually tailored based on current fittnes level and functional ability. As the Engage-PD program is a behavior change coaching program, intervention sessions are more self-directed (or self-determined) than prescriptive, and therapists work to develop participant relatedness in feeling connected. Participants are free to choose which exercises and activities they engage in, however specific instruction on exercises are provided as appropriate. Therapists work individually with participants to set goals, using a modified version of the Canadian Occupational Performance Measure (COPM), based on current activity levels and functional ability with particular concern for safety. The workbook also provides education on physical activity monitoring to support autonomy, which participants can do using wearable activity monitors, smartphones, or exercise diaries.

[H1] Adaptation for Telehealth: Barriers and Opportunities

In response to stay-at-home guidelines, the *Engage-PD* program rapidly transitioned to a telehealth platform within two weeks of state enforcement of restrictions on non-essential medical visits in New York. With regard to inclusion criteria, we modified our program to include individuals with mid-stage PD (Hoehn and Yahr stage III in addition to previously targeted stages I-II). This change was made in response to the increased demand for exercise and activity guidance by our patients, many of whom were struggling to restructure their exercise

routine to be conducted completely at home. All sessions were moved to telehealth platform using Zoom Video Communications , Inc. (San Jose, CA). The structure of assessments was also modified to exclude the TUG, 30sCST, and 10mWT. While these assessments could likely be completed by participants with instructions via Zoom, we were concerned about participant safety and reliability of the data. We weighed the risk/benefit ratio of this in our decision to eliminate these measures for the short-term. All other assessments were adapted for video interview.

The structure of the intervention sessions did not markedly change when implemented via telehealth, however we made some adaptations to address the current stay-at-home environment. As a coaching intervention, the *Engage PD* program consists mostly of 1:1 interactive discussion with participants, which easily translated to the telehealth environment. The original *Engage* program involved one follow up session via phone/videoconference. Our team believed additional sessions would be useful as participants were facing more difficult circumstances and could benefit from having the option of multiple follow up sessions, thus we increased the number of follow up sessions to four. With regard to educational materials, participants received a digital version of the Engage workbook via email, rather than a printed version. Therapists used the Share Screen option on Zoom to review aspects of the workbook with participants during sessions. With regard to exercise recommendations, stay-at-home guidelines required coaches and participants to jointly rethink their exercise routine and resources available to work within their environmental constraints.

From March 25-May 27 we received 52 referrals to program and enrolled 27 individuals for a recruitment rate of 52%. While direct comparisons with pre-coronavirus recruitment are difficult due to the recency of the Engage implementation study, this recruitment rate was larger

than expected, which may have been due to several factors. For the clinic-based *Engage* program, time restrictions and parking/transportation considerations limited the ability of some participants to enroll in the study on-site. Furthermore, many patients were fatigued after their neurologist appointments, and were not willing or able to extend their visit by another hour to participate in the program. The successful recruitment for the telehealth *Engage* program likely reflects the unique opportunity provided by stay-at-home guidelines. Most patients had limited, if any, access to in-person programs and therapy services during this time, and the Engage program filled an immediate need to provide exercise and activity guidance. The *Engage* program specifically aims to facilitate exercise uptake in the home or community environment, which perfectly aligned with stay-at-home guidelines.

Mean (SD) age for the 27 enrolled participants was 66.5 (8.6) years; 22 participants identified as white, 1 Asian, 1 Hispanic, 1 other, and 2 declined. For education level, we had incomplete data for 8 participants, 1 had some college, 2 had a college education, and 7 had advanced degrees. There was a wide range of scores for both baseline physical activity and self efficacy measures. Mean (SD) (range) Brunel score was 3.7(1.0) (1.0-4.7) for planned and 2.4(0.7) (1.3-3.3) for unplanned; Norman self efficacy was 56.8 (17.0; range 19-84)). All participants who enrolled in the program had access to technology (smartphone, tablet or computer) to use the Zoom platform. Four participants experienced technology difficulties that took longer than 15 minutes to address, but all participants were able to connect within the first session. Twelve participants had a carer or partner present during all or most of the sessions to date, either to help with technology or to observe the sessions.

[H1] Telehealth in Parkinson disease

Although telehealth programs have been used in rehabilitation for many years, there has been inconsistent uptake of such programs across the healthcare continuum. Since the onset of the coronavirus pandemic, such programs have surged to the forefront of healthcare delivery, with considerable state and federal efforts to change reimbursement policies. Furthermore, the American Physical Therapy Association (APTA)[24] and other organizations have provided important guidance and structure for remote delivery of physical therapy services, as well as reimbursement issues to ensure appropriate infrastructure is in place to support ongoing service delivery. Essential to this conversation is the structure of these programs, including physical activity coaching. Physical activity coaching should be a standard component of physical therapy intervention and is one that is highly amenable to remote delivery.

Most clinical studies that have investigated engagement of exercise in people with PwPD have been conducted in ambulatory settings, under tightly controlled conditions, and with use of direct supervision of trained healthcare personnel.[25] These studies and the subsequent evolution of applied health programs invoke many logistical barriers (cost, transportation, accessibility), which ultimately affect the reach, efficacy, and feasibility of targeted practice.[26] With advances in both technology and healthcare, telehealth platforms are becoming more prevalent as an effective tool to deliver timely healthcare service. Compared with face-to face delivery, interventions delivered via telehealth may increase accessibility of self-management interventions by addressing major barriers that may negatively affect patients' participation, including cost, mobility restrictions or service availability in remote rural areas.[27]

Telehealth interventions have produced positive clinical outcomes in a variety of chronic conditions.[28] The implementation of telehealth to service PwPD is certainly evolving, although remains in its infancy. A case-report detailing a telehealth program for an individual with PD

showed positive clinical health-related outcomes including functional mobility,[29] and furthermore, an investigation into a peer coaching program that included both in-person and telehealth platforms was deemed feasible, safe, and acceptable for use in PwPD.[25] Most recently, Ellis and colleagues[30] provided preliminary evidence in support of the feasibility and efficacy of a telehealth intervention in PwPD. In this study, individuals with PD who underwent a combined behavioral change and individualized exercise intervention via a mobile device showed improved rates of physical activity over the course of a year, in comparison to those receiving a similar program without use of technology. Patient preference for telehealth was also demonstrated in a feasibility study of the current *Engage* program in individuals with PD (Hoehn and Yahr stages I-II) , where 85% (11/13) of participants opted to do at least one session remotely via videoconference, and ultimately produced 100% adherence.[16] These studies have made headway in bridging the gap of providing innovative, patient-centered interventions to address sedentary behavior and promote physical activity uptake in PwPD.

In order to sustain exercise and physical activity for long term benefits, it is imperative that individuals are empowered through education and the development of self-management skills. To be successful, many individuals require support to develop necessary competencies such as problem-solving, decision-making, resource utilization, goal setting and action planning.[31] These skills, along with the support of a physical or occupational therapist, help to foster the formation of health-promoting habits and routines in their daily lives. Evidence suggests that self-management programs may yield better health outcomes and longer uptake of exercise and physical activity in people with chronic diseases[32] and neurological diseases[33] compared to non-self-management programs.[34] Importantly, such self-management programs, which are largely focused on 1:1 discussions, may be highly amenable to telehealth delivery.

[H1] Looking forward

With change comes opportunity, and the vision as well as clarity of thought that can emerge in times of uncertainty. The coronavirus pandemic has forced a dramatic shift in the management of PwPD as well as health-related behaviors of the individual. With many hospitals and outpatient facilities providing limited in-person treatments, and social distancing or stay-at-home orders in place throughout much of the country, PwPD have had reduced access or ability to engage in physical activity and exercise. As social distancing restrictions begin to ease, PwPD may choose to stay at home rather than risk exposing themselves to infection. This may be the opportune time to begin more widespread implementation of telehealth programs for physical activity coaching in PwPD.

While delivery of the Engage program via telehealth is relatively new, analysis of the feasibility of implementation is essential to inform future modifications. While recruitment rates were initally high, we had a low racial and educational diversity in our early referrals. A critical gap in provision of services for PwPD is toward the Hispanic/Latinx and African American/Black communities and to develop targeted strategies for recruitment and inclusion of these groups in telehealth programs. Individuals in these communities may have limited access to disease-specific exercise and physical activity advice, and Hispanic and African American PwPD are less likely to access rehabilitation services compared to Caucasians.[35] For many PwPD there is a need for expert guidance to overcome barriers, set realistic goals, and provide personalized advice adapted to their culture and in their native language to optimize exercise uptake and adherence. Importantly, a multi-faceted approach is needed to address individualized needs and

consider linguistic and cultural differences in diverse communities found in New York City. Moving forward, we plan to implement specific efforts for a more diverse representative sample and to consider cultural adapations to the program. Furthermore, there may be barriers to telehealth services more generally, including internet access and digital competencies, that would require systematic efforts to address.

With the uncertainty brought about by the current pandemic, it is advantageous to alter the current model of care. Emphasis on early stage management, self-management and coaching interventions[9] that can be readily implemented via telehealth are essential. Changing models of care, whereby individuals with neurodegenerative diseases such as PD can be monitored periodically over an extended period, can potentially improve cost effectiveness of rehabilitation services as well as outcomes for disease management. Such models would not replace short intensive episodes of care as needed, but would rather provide a more comprehensive model that emphasize a patient-centered approach to managing a complex, lifelong disease such as PD.

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Ethics Approval

Engage-PD was approved by Columbia University Medical Center's Institutional Review Board (IRB # AAAS4709).

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Disclosures

The authors completed the ICMJE Form for Disclosure of Potential Conflicts of Interest and reported no conflicts of interest. Dr Quinn is a member of PTJ's Editorial Board.

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Figure Legends
Figure. Logic model framework for the Engage-PD Physical Activity Coaching Program.