Amp'd for Parkinson's Program Proposal

Background

The most common gross motor symptoms experienced by patients with Parkinson's Disease (PD) are gait disturbances, postural instability and poor balance, rigidity, slowness of movement, and tremor.[1, 2] A community-based program that targets these deficits can aide in reducing risk of falls and subsequent injuries, while preventing further functional decline and maintaining current levels of mobility, strength, balance, and therefore quality of life. Increased physical activity, whether through dance therapy or amplitude training have been shown to improve several functional outcomes and patient reports of quality of life.[3-6]

Dance therapy, specifically the Argentine Tango, is known to improve gait speed, static and dynamic balance, cognition, and reduced risk of falls when performed over in a group setting.[3] Further gait mechanics, such as pace length, gait variation, coordination, and speed of cadence can be improved following a period of dance training. [4, 5] In addition to these motoric benefits, cognition, relaxation, emotional well-being, independence with activities of daily living, and operational memory may be enhanced following dance therapy with rhythmic, musical stimulus as part of the therapy.[4] While the exact parameters for the dance interventions are not known, generally 1-hour long sessions that consisted of 5-10 minutes of dancing warm up with music, 15-20 minutes of dance instruction, and 5-10 minutes of free/partner dance resulted in improved motor, psychosocial, and quality of life outcomes as previously described.[3, 4, 5]

Additional motor, cognitive, and quality of life outcomes can be improved following a period of amplitude-based training, such as the LSVT BIG protocol. After this

program, individuals demonstrated improved functional mobility, gait speed, cognition during dual tasking, and improved self-confidence with regard to risk of falls.[6, 7] After amplitude-based training that consisted of stretches and multidirectional movements for the whole body, individuals with PD were able to perform functional tasks, such as transfers, dressing, and walking with greater speed, amplitude, and safety.[8]

There is evidence to suggest that self-management of PD through group-based exercise interventions can promote increased self-efficacy, quality of life, a sense of belonging, safety, and joy.[9,10] Rooted in the Social Cognitive Theory (SCT) this program emphasizes the role of social support and self-efficacy in the management of chronic health conditions.[9] Establishing and maintaining a sense of community is seen as nearly as important as the benefits of the exercise itself, as reported by participants in community-based exercise programs for individuals with PD.[10] This literature demonstrates that interventions at the individual level, and social support at the community level can promote optimal health and quality of life outcomes for patients with PD. According to the Social Ecological Model, it is important to consider individual factors such as levels of motivation, attitudes toward diagnosis and interventions utilized, as well as skills and activities of interest and importance to the person.[11, 12] At the interpersonal level, it is important to consider methods of social support, both in family members and caregivers, as well as individuals with similar health and functional status in order to build community among all parties involved.[11, 12]

Functional and quality of life improvements can be measured from a series of formal outcome measures, both performance-based and patient-reported. This program will utilize the Timed Up and Go (TUG), the Five Times Sit to Stand (5STS), and the

Parkinson's Disease Questionnaire-39 (PDQ39) for assessment of functional mobility, gait speed, risk of falls, quality of life, and psychosocial factors that play a role in independence and the previously mentioned parameters.

The TUG is a brief, performance-based outcome measure that assesses functional mobility and provides information about the individual's risk of falling. In patients with PD, the TUG has excellent reliability and validity, and it is highly recommended by the PD EDGE for use in Hoehn and Yahr stages I-III.[13] There are different normative data and falls risk categorization according to Hoehn and Yahr staging and "on" versus "off" phasing of medications. While risk of falls increases with increasing TUG time, the general cutoff score for individuals with PD is 11.5 seconds (greater than this indicates increased falls risk).[13,14] Some sources indicate that a TUG time greater than 7.95 seconds during "on" phasing of medication indicate increased risk of falls, but for the purposes of this program, 11.5 seconds will be utilized as it is more inclusive of all levels of participation.[13]

Another excellent outcome measure for this program is the 5STS. This measure assesses functional mobility for transfers, general lower extremity strength, and risk of falls. The 5STS has excellent reliability, adequate to excellent validity, and is highly recommended for use in Hoehn and Yahr stages I-IV by the PD EDGE.[15] The cutoff score for this test is 16 seconds, as anything greater than this indicated increased risk of falls. It is important to note that a floor effect may occur if the individual is unable to rise from the chair without the use of their upper extremities. In this case, the results of the TUG test would be the focal outcome measure for the participant regarding risk of

falls. However, the 5STS test should still be completed to assess for functional mobility and general lower extremity strength, noting use of upper extremities as appropriate.

Finally, the PDQ39 is a patient-reported outcome measure that assesses PD-specific quality of life, focusing on areas of functional mobility, activities of daily living, psychosocial factors, and cognition. The PDQ39 has adequate to excellent reliability, consistency, and validity, and is highly recommended by the PD EDGE for use in all Hoehn and Yahr stages.[16] Because this is the longer version of the assessment (an 8-item version with great psychometric properties is available), it will take longer to administer, but will also provide a more comprehensive assessment of the patient's perception of quality of life related to their condition.[17] Utilizing the more detailed form may also help with tracking disease progression, which could be useful information for their physician or neurologist and their overall healthcare. If the full version of the PDQ is not well tolerated by participants, the 8-item version will be used for ease of administration and brevity.

This community-based program will aim to improve functional mobility, strength, balance, and quality of life through dance therapy and amplitude-based training. The group atmosphere is also expected to have positive effects on the participants' quality of life and psychosocial factors that play a role in physical functioning. Utilizing the evidence to design interventions and assess outcomes will optimize the outcomes of this program, and ideally result in functional improvements and/or prevent functional decline in adults with Parkinson's Disease.

Program Goals

1. In 12 weeks, the participant will improve Timed Up and Go (TUG) time by at least 4 seconds to demonstrate improved functional mobility and reduced risk of falls.[13]
2. In 12 weeks, the participant will demonstrate improved functional mobility and reduced risk of falls through performance of the Five Times Sit to Stand (5STS) test in less than 16 seconds.[15]
3. In 12 weeks, the participant will show an improved Parkinson's Disease Questionnaire-39 (PDQ39) score of at least 12 points across *mobility* domain items to demonstrate self-perceived improvement in functional mobility and quality of life.[16]
4. In 12 weeks, the participant will show an improved PDQ39 score of at least 14 points across *emotional wellbeing* domain items to demonstrate self-perceived improvement in quality of life and psychosocial health.[16]
5. In 12 weeks, the participant will report at least 80% satisfaction with the *Amp'd for Parkinson's* Program according to the patient satisfaction survey in Appendix A to demonstrate a generally positive perception of the program and provide an outlet for participant feedback.

Methods

The Participants

This program, *Amp'd for Parkinson's,* is best suited for individuals with Stage I-III Hoehn and Yahr Parkinson's Disease, as individuals in these stages generally have unilateral or bilateral involvement and some postural and balance instability, but are typically still independent for activities of daily living (ADLs) and ambulation.[1] Stage IV

on the Hoehn and Yahr scale is typically when some assistance is needed for ADLs and ambulation, and Stage V indicated full assistance required for these tasks.[1] Individuals in Stage IV and V will not be excluded from participation, but will likely require greater levels of assistance and/or lower levels of participation in the program. In terms of advertising materials and communication with the general community, the target population will be "individuals with Parkinson's Disease" and participation from a life partner or caregiver will also be encouraged (but not required). For individuals who participate in the program alone, they will be partnered with a staff member or volunteer who would be recruited from local organization such as pre-health student groups and health professional programs at UNC and Duke. The program will be advertised to healthcare professionals at UNC' Parkinson's Foundation Center for Excellence and Duke's Parkinson's Disease and Movement Disorder section of the Department of Neurology for patient referral. Fliers will also be posted at the Orange County Senior Center, Chapel Hill Public Library

Program Description

Amp'd for Parkinson's will be offered at the Chapel Hill Public library, which includes a large projector screen, sound system, WiFi access, and can be rented at no cost for community groups that are advertised to the public.[18] This program will operate for 12 weeks at a time, with 2 1-hour sessions per week. While exact recommended intervention dosage is unclear in the literature, most programs consist of 2 ~60-minute sessions per week for 10 to 13 weeks, with some programs operating for 12 months and longer.[3-5] Because the program runs for 12 weeks, there will be quarterly opportunities for outcome assessment, renewed sign up and participation, and new

participant sign up. Ideally, participants will continue through successive seasons of the program in order to continue maximizing outcomes for function, quality of life, and social support.

Each session will consist of 5-10 minutes of warm up through walking, full-body amplitude-based stretching, and directional changes associated with rhythmic musical cues. Following this warmup period, approximately 15-20 minutes of Argentine Tango consisting of frequent initiation and cessation of movement at different speeds, rhythmic variations, and small multi-directional perturbations according to typical tango fashion.[19] Dance instruction will be provided by a previously trained professional dance instructor, recruited from either the American Dance Festival in Durham, NC, UNC and Duke affiliates, or other dance studios in the local community.[20] To maintain safety, the person in the supportive role (without PD) will be trained on these dance moves and interventions as an introduction in the first several sessions. Those participating in the partner role will provide physical support by holding the participant's forearms and responding to changes in balance and direction from the participant and the dance protocol. They will also contribute to the psychosocial support aspect of the program, as they help to build the participant's confidence and physical function capabilities, as discussed in the Social Cognitive Theory.[9, 10] Participation in the group setting with partners and interaction with other individuals will provide a positive experience that promotes safety, a sense of belonging and inclusivity, joy, and intrinsic and extrinsic motivation.[10] After the guided dance intervention, participants will have 5-10 minutes of free dance with their partner, and during non-COVID times, will be allowed to swap

partners if desired. This portion of the session will promote a sense of self efficacy and allow participants to take an active role in their physical activity and participation.

A short break will be provided, if necessary, following the dance portion of the session. At this point, the second phase of the session will begin, focusing on amplitude-based training for 15-20 minutes. While the Lee Silverman Voice Treatment BIG (LSVT BIG) protocol is often considered a "gold standard" for Parkinson's physical therapy, research has shown benefits associated with amplitude-based exercise that differs from the LSVT BIG protocol.[7] In the first 2 weeks, amplitude exercises will start at a lower intensity, focusing on seated multidirectional reaching exercises, and gradually progressing toward full functional amplitude based movements, according to the chart below and the LSVT BIG exercises.[21] Each week will incorporate tasks from the previous weeks in order to truly build intensity and duration throughout the program and within each session. Participants will be encouraged to practice these activities at home with family members and/or caregivers, further incorporating social support into their regular physical activity routines as encouraged in the Social Cognitive Theory.

Amplitude Exercise Progression	
Weeks 1-2	Seated, multidirectional reaching
Weeks 3-5	Standing, forward and sideways reaching
Weeks 6-7	Standing, all direction reaching
Weeks 8-10	Standing, rocking and rotation with reaching
Weeks 11-12	Functional movements (sit to stand)

Each session will conclude with about 5 minutes of stretching and cool-down, and the instructors will be available to answer any questions and provide any feedback necessary at the end of the session. Participants will be made aware that any feedback or answers to questions should not substitute for medical advice, and if they have a medical concern, they should seek care from a member of their healthcare team.

Participant Assessment

Each participant will complete the three outcome measures before and after the full program protocol. Participants will be asked to arrive ~15 minutes early at the first and final sessions to allow time for completion of these measures. The TUG and 5STS will be administered by the instructors, and participants will complete the PDQ-39 individually or with the assistance of their partner or caregiver. The PDQ-39 will also be sent electronically in case one prefers to complete this form in advance of the session. Results of each measure will be recorded and securely stored on the lead physical therapist's computer, and hard copies will be disposed of appropriately. For individuals participating in successive rounds of the program, the post-test for the earlier round may serve as the pre-test of the next round. Results of these evaluation methods will be communicated to the participant, and concerning results will prompt a more detailed conversation with the participant regarding follow-up care with a physical therapist or physician. Participants will also be asked to complete a participant satisfaction survey (included in Appendix A) as a method of program evaluation and to provide an opportunity for participants to provide feedback to instructors.

Instructors and Training

Instructors for the program will be physical therapists and dance instructors in the community who have an understanding of the program goals and interventions, outcome measures, and basic information about Parkinson's Disease and the associated physical and functional impairments. The primary physical therapist will be responsible for educating the additional instructors on typical presentation and impairments of Parkinson's Disease through a brief lecture and discussion style presentation, administration of the outcome measures (TUG, 5STS, and PDQ-39), and implementation and rationale for the program interventions (Argentine Tango and amplitude training). As previously discussed, the dance instructor will be trained in Argentine Tango style of dance, and will provide all dance instruction in the program. Education and training will be provided to all new instructors, and will be reviewed bi-annually.

Program Funding

Prior to implementation, this program will apply for a grant through the Parkinson's Foundation, which has pledged $1 million for community-based programs in 2021, ranging from $5,000 to $25,000 per program.[22] These funds are generally awarded to community-based programs that serve newly diagnosed individuals, underserved populations, and address mental health concerns through wellness and exercise.[22] Ideally, a small grant will be given to fund the pilot season(s) of this program, and funds will be increased as program goals are met and the lives of more community members with PD are improved. If the grant is not awarded, other methods of funding

will be explored, such as the Parkinson's Association of the Carolinas and the Orange County NC Department of Health.[23-25]

COVID-19 Adjustments

To accommodate for local health and safety guidelines for COVID-19, 10 total participants (individuals with PD and their guests/partners) will be allowed to participate in person, and there will be a virtual option for each session (via live Zoom and recorded video). For the in-person sessions, the floor will be lined with tape in a grid-like fashion to maintain at least 6 feet of physical distance between participant partnerships. Masks will be required, and health screening will be implemented prior to in-person participation.

Program Evaluation

Participants in the *Amp'd for Parkinson's* program will be evaluated as previously described through performance of the TUG, 5STS, and completion of the PDQ-39. Goals will be assessed by comparing pre-test data to post-test data from these outcome measures. Goals may be re-evaluated and progressed for individuals who participate in successive rounds of the program. Formal program evaluation will occur bi-annually through an organized discussion between founders and instructors, and volunteers will be invited to share feedback as well. Data from the outcome measures and patient satisfaction surveys will be reviewed, and program goals will be updated appropriately based on participant data and realistic expectations for participant improvement.

Program evaluation discussions will be rooted in the framework provided by the United States Centers for Disease Control & Prevention Self Study Guide on Program

Evaluation. Items to be discussed include: program implementation, effectiveness, efficiency, cost-effectiveness, and attribution.[25] The form in *Appendix B* will serve as a guide for the program evaluation, and will guide any necessary changes to the program. All individuals present at the program evaluation meetings will be asked to complete the form and provide relevant feedback and suggestions.

Strengths and areas for improvement of the program will be discussed, and an action plan will be developed for each area of improvement. At least one person will be identified as the "point person" for each action plan, with a realistic timeline established for each course of action and change to be implemented. Changes to the program will be evaluated at the next program evaluation meeting, and further updates will be discussed if needed.

Conclusion

Amp'd for Parkinson's is a 12-week community-based program for individuals with Parkinson's Disease. It will address the physical impairments commonly present among individuals with PD, including reduced balance, functional mobility, strength, and slowness of movement.[1-8] Participation in regular physical activity, especially those focused on Argentine Tango and amplitude-based training can have positive effects on gait speed, balance, quality of life, and reduced risk of falls.[3-8] Exercise in a group setting, especially with those who experience similar physical and functional impairments can have great psychosocial effects for individuals living with PD.[9-10] This program will provide access to a safe environment for regular exercise and social support at no cost to the participants. Participants will be assessed for physical and

quality of life improvements, and the program will be evaluated regularly to optimize participant outcomes, utilization of current evidence, and efficacy of the program overall.

Appendix A

Participant Satisfaction Survey:

Please rate your level of agreement with the following statements by checking the box that most appropriately reflects your opinion(s). Feedback will remain anonymous, unless you prefer to provide your name and contact information for follow-up.

	Strongly Disagree (1)	Disagree (2)	Neutral (3)	Agree (4)	Strongly Agree (5)
I am satisfied with my experience in the *Amp'd for Parkinson's* Program.					
I would recommend the *Amp'd for Parkinson's* Program to others.					
I felt safe during the activities performed throughout this program.					
I learned something from the *Amp'd for Parkinson's* Program.					
I will use skills that I learned in this program in my day to day life.					
I would like to sign up for another session of the *Amp'd for Parkinson's* Program.					

Comments/Suggestions:

Questions for Instructor(s):

Appendix B

Program Evaluation Form

Evaluator Name and Role:_____ Date:_____

The chart below will serve as a framework for program evaluation discussion. Please provide your thoughts and suggestions as appropriate.

Facet	Question(s)	Met Expectations or Needs Improvement	Suggested Action Steps and Point Person(s)
Program Implementation	Were the program plans were put into place as anticipated?		
Effectiveness	Did the program achieve its goals as initially described?		
Efficiency	Have program plans been implemented with appropriate use of resources (time, space, technology, funding)?		
Cost-Effectiveness	Does the value of achieving program goals exceed the cost of implementing the program? Is there adequate funding to continue implementing the program as currently designed?		
Attribution	Can progress toward program goals be specifically related to program interventions? Is there updated literature that suggests interventions should be modified or updated?		

Additional notes/suggestions:

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