Communicative participation in Parkinson's Disease: An SLP's glimpse into associations with variables from a tandem cycling exercise program

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Abstract

Communicative participation in Parkinson’s Disease: An SLP’s glimpse into associations with variables from a tandem cycling exercise program

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Purpose: 1) Examine communicative participation and other speech-related variables as secondary outcomes of a community-based exercise program for people with Parkinson's disease, 2) Examine characteristics of participant groups based on their CPIB scores, 3) Examine stability of CPIB over time. *Method:* Analyzed participant outcomes from tandem cycling study. Data included responses to the CPIB; physical outcome measures such as gait speed, Timed up and Go, and Five Time Sit to Stand; and self-report data relating to activities of daily living, Parkinson’s severity, depression, and cognition. *Results:* Better communicative participation was associated with less difficulty with speech, tremor, quality of life, and overall functioning in activities of daily living. Participants with lower CPIB scores appeared to differ in specific variables from those with High CPIB scores on gender, ADL difficulty, and QOL, and many self-report variables. There was no significant difference between CPIB scores pre to post intervention. *Conclusions:* Communicative participation is complex and influenced by many variables. CPIB scores were stable over time at the group level, but individual changes were seen suggesting the need for assessment of communicative participation on a person-by-person basis.

Introduction

People with Parkinson's disease (PD), as with many other disordered populations, are consistently seen by various health professionals over the course of their disease to help manage the different symptoms that arise. McGough et al. (2016) recently conducted a study that reported on the feasibility of a community-based exercise program for people with PD. In the study's infancy, McGough and colleagues collaborated with speech pathology researchers at the University of Washington and decided to gather speech outcome data as a control measure in addition to the outcome measures of physical function and many other pre-determined variables such as cognition, depression, QOL, and PD symptom severity that were being explored by the physical therapy researchers. The collection of data offered a unique opportunity to get a glimpse into PD from the perspective of these two professional domains and explore relationships between the two within the context of PD. McGough and colleague's 2016 article reported the results regarding feasibility of the exercise program and changes seen in participants' outcome measures. Speech data were not addressed at that time. Thus, the current study sought to perform a secondary data analysis from the primary study from the perspective of speech pathology. The primary speech outcome measure of interest was the Communicative Participation Item Bank (CPIB) which had been undergoing research to strengthen its psychometric properties. The current study continued the CPIB exploration and sought to provide a glimpse into relationships between speech and physical function; as well as to explore the stability of the CPIB over time.

The following literature review highlights the classic motor symptoms of PD as well as how these symptoms are viewed and addressed within the fields of physical therapy and speech pathology. The current psychosocial medical model and how it has shaped clinical practice is addressed briefly. McGough et al.'s (2016) tandem cycling program and the concepts underlying its design are explained in greater detail, and the history of the CPIB as a measurement tool in speech pathology is described in order to provide a better understanding for the rationale behind the current study.

Literature Review

Parkinson's Disease

Parkinson's disease (PD) is a progressive neurological disorder. It was first described in 1817 by James Parkinson. PD affects approximately 1% of people over the age of 60 years, rising as high as 4% as age approaches 80 years (de Lau & Breteler, 2006). PD is characterized by four cardinal signs: bradykinesia, rest tremor, rigidity, and loss of postural reflexes. The first sign, bradykinesia, stems from disruptions in the basal ganglia and presents as slowness of movement. It is often manifested by shuffling gait and decreased blink rate that causes a staring facial appearance common in persons with PD. The second, rest tremor, is an easily recognized characteristic that occurs mostly in the hand and occurs at a frequency of 4-6 Hz. Rest tremor is related to alternating contractions of muscles versus other tremors which are higher frequency and have simultaneous muscle contraction (Dewey, 2000; Jankovic, 2008). The third feature – rigidity – is defined as increased resistance, particularly within the range of passive movement of a limb. This is due to high muscle tone and the alternating contractions that occur in the rest tremor. This manifests itself as a jerky resistance referred to as "cogwheeling" (Dewey, 2000). Another aspect of rigidity that affects people with PD is a motor block called "freezing" which is a form of akinesia that usually appears as a sudden halt in forward movement. Rigidity is accompanied by the fourth and final characteristic of PD, postural deformities and postural instability which result in gait and balance difficulties. (Dewey, 2000; Jankovic, 2008).

In addition to the four cardinal signs, some secondary motor symptoms include re-emergence of primitive reflexes and bulbar disruption (e.g., dysarthria, hypophonia, dysphagia, and sialorrhea). Autonomic systems may also be impacted and result in problems such as orthostatic hypotension, constipation, sweating, urinary problems, and sexual dysfunction. Non-motor symptoms such as cognitive/behavioral domains and sleeping cycles have been shown to be affected as well, often in later stages of the disease (Hely, Morris, Reid, & Trafficante, 2005). PD can also present with sensory abnormalities, in particular, olfactory dysfunction. Official diagnosis can only be made post-mortem. However, clinicians currently diagnose PD when people present with the cardinal motor features and their associated symptoms, have a positive response to levodopa, and an absence of exclusionary symptoms (e.g., signs more associated with essential tremor) (Dewey, 2000; Jankovic, 2008).

The motor symptoms of PD are managed via a variety of methods. One of the most common and effective methods has been through medication management directed at reversing the dopamine deficiency. Currently, the primary medication used for people with PD is levodopa, however, other medications such as direct acting dopamine agents and drugs that inhibit glutamate neurotransmission are also employed depending on time of disease onset and other factors (Ahlskog, 2007). Surgical management of PD motor symptoms is also a possibility for many people including procedures such as pallidotomy, thalamotomy, subthalamotomy, cerebral transplantation, and gene therapy. These surgeries have had varying degrees of success (Shannon, 2000). One of the most effective surgical procedures for management of Parkinsonian tremor is deep brain stimulation (DBS) which places electrodes within the brain that provide a continuous stimulus to specific sites. Studies have shown improvement in all four cardinal PD motor symptoms, depending on the loci of the stimulation (e.g., ventral intermediate nucleus, internal globus pallidus, or subthalamic nucleus) (Shannon, 2000; Walter & Vitek, 2004).

PD in Physical Therapy and the Tandem Cycling Program

Physical therapists (PTs) play a vital role in symptomatic treatment of PD motor symptoms. A systematic review of literature on physical therapy in PD defined the core areas of PT in PD to be aiding in transfers, posture, reaching and grasping, balance and falls, gait, and physical capacity (Keus, Bloem, Hendriks, Bredero-Cohen, & Munneke, 2007). Each of these areas can be addressed by PTs and aid in managing the symptoms that accompany PD. Specifically, the authors of the systematic review suggest physical therapy can improve a person with PD's physical capacity through means such as exercise programs. Results of the review also suggested that such interventions could plausibly increase muscle power in people with PD. Not directly related to PT, but ultimately influential, other researchers began to investigate a phenomenon called forced exercise; exercise in which the individual is forced to maintain speed greater than their preferred rate. This was first explored in animals and subsequently human subjects (Alberts, Linder, Penko, Lowe, & Phillips, 2011; Ridgel, Vitek, & Alberts, 2009). Based on positive results and recognizing the aforementioned role of PT in PD intervention, researchers sought to integrate the concept of forced versus voluntary exercise into an exercise program. Introducing forced exercise into the PD population was hoped to help them reach a moderate level of exercise which could help improve their physical capacity (Ridgel et al., 2009).

For the forced exercise study by Rigdel et al. (2009), participants with PD were placed on tandem bicycles with a healthy partner. With the healthy partner setting the pace, the people with PD were encouraged to exercise at a target heart rate (THR) consistent with moderate intensity aerobic exercise. Observation of a comparison group of people with PD performing voluntary exercise – exercise performed at an individual's preferred rate – revealed that overall, they were unable to reach the THR and thus not reach the moderate level of exercise. The study also revealed greater improvements in upper extremity motor control and gait in those who participated in the forced exercise group (Rigdel et al., 2009).

McGough et al. (2016) noted these improvements and set out to utilize this theory in a program designed to overcome many of the barriers to participation that persons with PD experience. McGough and colleague's tandem cycling program highlighted the need for thinking beyond traditional functional gains, and suggested that a community-based exercise program in early PD could have long-term potential to increase regular physical activity (Rafferty & Corcos, 2016). Thus, McGough and colleagues implemented the 10-week tandem cycling exercise program in collaboration with community partners (McGough et al., 2016). The study ultimately revealed that the exercise program was not only feasible based on attendance and retention, but the participants also demonstrated improved physical outcomes across domains of gait, balance, and mobility, suggesting a slowing or reversal of functional decline as a result of the cycling program. The exercise could potentially provide a viable way for people with PD to meet recommended aerobic exercise levels for older adults. Having the volunteer biking partners was suggested to have improved an individual's confidence which has been shown to be a positive predictor of participation in exercise programs (Ellis et al., 2011).

PD in Speech Pathology

While physical therapy approaches address motor symptoms of PD, speech pathologists also play a role in management of the motor symptoms and their effect on speech as caused by basal ganglia disruption. Logemann reports that 70-89% of people with PD have hypokinetic dysarthria (Logemann, Fisher, Boshes, & Blonsky, 1978). Bradykinesia and rigidity are two driving forces behind the speech characteristics found in PD. These symptoms affect a person's speech at three levels: respiration, phonation, and articulation (Canter, 1965; Duffy, 2000; Ramig, Sapir, Fox, & Countryman, 2001; Streifler & Hofman, 1983).

Researchers have found evidence that decreased respiratory support influences the speech of people with PD (Canter, 1965). This manifests itself as reduced excursion of the chest wall and abdomen, and is noted perceptually as reduced loudness. This has also been noted as a potential factor in reduced prosodic variability and monoloudness (Duffy, 2000; Streifler & Hofman, 1983). Phonatory problems are manifest through a breathy or hoarse voice and sometimes a vocal "flutter" upon sustained phonation. The hypokinetic nature of the symptoms which causes the reduced prosodic variability mentioned above can cause a voice to be monopitch. These symptoms were found to the most common amongst co-occurring symptoms in a study of 200 people with PD (Duffy, 2000; Logemann et al., 1978).

Impairment of speech and voice are caused by different components of speech affected by PD acting together (Streifler & Hofman, 1983). The strength and symmetry of the jaw, face, and tongue may be surprisingly normal, but reduced range of motion may be evident in these structures during diadochokinetic (DDK) tasks. Rigidity can cause a person to have trouble initiating movement which can result in long pauses between phrases. Many people with PD also speak at an accelerated rate. When the long pauses and accelerated rate occur at the same time, people with PD are perceived as talking in short rushes of speech (Canter, 1965; Duffy, 2000; Logemann et al., 1978).

All of the speech symptoms associated with PD can result in a significant reduction in speech intelligibility. This has been well documented (Duffy, 2005) and verified through research focused on measuring dysarthria severity through the development of the Speech

Intelligibility Test (SIT) (Yorkston, Beukelman, Hakel, & Dorsey, 1996). In this assessment, the speaker with dysarthria reads a set of sentences of increasing length from 5-15 words. Unfamiliar listeners transcribe recordings of the sentences, and a score in terms of percentage of words correctly transcribed is generated to represent the speaker's intelligibility.

Just as ways to manage the motor symptoms of PD have been developed over the years by physical therapists, treatment approaches have also been explored by speech pathologists that address the hypokinetic dysarthria that accompanies PD. The Lee-Silverman Voice Treatment (LSVT) (Ramig et al., 2001) is a speech intervention that has substantial evidence in its ability to improve the speech of people with PD (Fox et al., 2006; Fox, Ebersbach, Ramig, & Sapir, 2012; Ramig et al., 2001). Researchers have documented improved phonation through perceptual ratings and sound pressure level (SPL) output as well as improved articulation, facial expression, and swallowing for people with PD. Additionally, in a study that used the Speech Intelligibility Test (SIT) as their outcome measure before and after LSVT treatment, the results indicated improved intelligibility amongst participants (Cannito et al., 2012). High levels of success in LSVT have been hypothesized to be because of their training across the speech production mechanism by choosing a single behavior (e.g. "loud") that targets the proposed pathophysiological mechanisms underlying bradykinesia/hypokinesia. Because of such broad ranging improvements in speech, researchers applied the principles of LSVT Loud and created a treatment for exercise and limb movement called "LSVT Big" (Fox et al., 2012). While the LSVT programs were not included in this current study, the precedent they provide in the literature of using similar approaches to address both speech and physical function did lend motivation for this study to explore any possible connection between a global physical exercise program exercise program and any possible speech outcomes.

Another symptom addressed by speech pathology is that of cognitive decline with approximately 80% of people with PD also demonstrating cognitive changes in some capacity (Hely et al., 2005). Approximately 10-30% of people meet diagnostic criteria for disabling dementia (Dewey, 2000; Montgomery, 2000), and may experience other cognitive symptoms such as slowed thinking (bradyphrenia) and executive function disruption characterized by loss of planning and goal-directed thinking. Each of these symptoms can cause significant impact on the daily life of a person with PD and their primary communication partners (Dewey, 2000; Jankovic, 2008; Montgomery, 2000).

WHO-ICF Model and PD

This study was motivated in part by an effort to understand how interventions targeted at one aspect of living with PD – in this case, motor aspects targeted by physical exercise intervention – might influence other aspects, such as speech. This relates closely to current biopsychosocial models of intervention. In the past, healthcare providers defined health conditions using a medical model of disability which only addressed biological factors of an illness or injury. In the field of speech-language pathology, this consisted of assessing and treating communication disorders by measuring body structures (e.g., mouth, tongue, lips, pharynx, larynx, etc.) and function (e.g., voice quality, speech intelligibility, accuracy of language content and grammar, etc.), and basing rehabilitation at this level. This prior approach failed to acknowledge contextual factors that could also contribute to a person's disability (Eadie, 2001; Threats, 2007) and which might also be targets for intervention. In 2001, the World Health Organization (WHO) adopted a new biopsychosocial model which, by definition, takes into account not only the physical impairment and performance of tasks, but the personal and environmental factors as well. This model is called the *International Classification of Functioning, Disability, and Health* (ICF) (Eadie, 2001; WHO, 2001).

The WHO-ICF provides clinicians with unified language to describe health and health related states on four levels: 1) body structures and function, 2) ability to perform activities, 3) participation in life roles, and 4) contextual factors. Disruption at any one of these levels can affect a person's life. The WHO-ICF stresses the importance of each of these levels and the cascading effect any one of them has on another.

Before the introduction of the WHO-ICF model, speech-language pathology clinicians and researchers had noted the limitations of assessing and treating people primarily at the level of body structures and functions (Yorkston, Klasner, & Swanson, 2001). Most assessment tools and treatment protocols did not address factors such as overall ability and fulfillment of communication acts in the contexts in which they occur. However, it is well documented that the life of a person with a speech-language disorder is affected daily during social interactions due to communication's intrinsically social nature (Baylor, Burns, Eadie, Britton, & Yorkston, 2011; Miller, Noble, Jones, Allcock, & Burn, 2008; Walshe & Miller, 2011). Thus, clinicians highlighted the need for assessment tools that address more of the life participation-related aspects of a communication disorder (Yorkston et al., 2001). Recognizing that the ICF brought these concepts together, the American Speech and Hearing Association (ASHA) adopted the ICF in the 2001 *Scope of Practice in Speech-Language Pathology* and in the Preferred Practice Patterns for the Profession of Speech-Language Pathology in 2004. This has been followed by greater attention on the part of clinicians and researchers to developing assessment tools and interventions focused more on the impact of communication disorders on life participation.

The Communicative Participation Item Bank

The introduction of the ICF model into a speech-language pathologist's (SLPs) scope of practice, assessment, and treatment helped SLPs to address communication in social contexts, also referred to as *communicative participation* (Eadie et al., 2006). Research revealed the significant impact of communication disorders on individuals' communicative participation (Miller et al., 2008; Miller, Noble, Jones, & Burn, 2006; Yorkston et al., 2001). Results from an examination of existing self-report measures to determine how well they were addressing this construct indicated that no existing measure was wholly adequate for measuring communicative participation (Eadie et al., 2006).

Upon discovering the paucity of assessment tools that measured communicative participation, researchers at the University of Washington began to develop a measurement tool known as the Communicative Participation Item Bank (CPIB). This outcome measure has gone through several iterations of psychometric testing and has been shown to be a reliable and valid measure of communicative participation (Baylor et al., 2013, 2011; Baylor, Yorkston, Eadie, Miller, & Amtmann, 2009; Yorkston et al., 2008). Additional research has suggested that the CPIB is valid for use with for multiple populations, and even multi-culturally (Baylor et al., 2014). In particular, research was conducted within PD populations and the CPIB has been shown to accurately represent their experiences (Baylor et al., 2013, 2014; McAuliffe, Baylor, & Yorkston, 2016).

In order to better understand both the construct of communicative participation and the performance of the CPIB instrument, a series of regression analyses were conducted in populations such as PD, multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS) and head and neck cancer patients (HNC) (Baylor, Yorkston, Bamer, Britton, & Amtmann, 2010; Bolt, Eadie, Yorkston, Baylor, & Amtmann, 2016; McAuliffe et al., 2016; Yorkston, Baylor, & Amtmann, 2014; Yorkston, Baylor, & Mach, submitted). Self-reported speech severity was a significant predictor of CPIB scores across all groups. Other factors were found to influence communicative participation across disorders such as fewer problems with fatigue, cognition, and emotion in PD (McAuliffe et al., 2016); speech usage, cognitive limitations, physical activity, and level of education in MS (Baylor et al., 2010; Yorkston et al., 2014); speech usage and swallowing in ALS (Yorkston et al., submitted); and laryngectomy status and time since diagnosis in HNC (Bolt et al., 2016). To date, however, no studies have looked at the stability of the CPIB over repeated measures.

Purpose

Early studies looking at relationships among variables and communicative participation raise questions about how communicative participation could be impacted not only by traditional speech-focused intervention, but by other interventions targeting other aspects of impairment, activity performance, or context in other domains. Explorations of these relationships may inform future, more holistic approaches to helping people live successfully with PD. To that end, this study involved a secondary analysis of CPIB, speech-related data, and physical performance data collected in the context of the broader study on the impacts of augmented aerobic exercise via tandem cycling conducted by McGough et al. at the University of Washington. As aforementioned, McGough and colleagues included the CPIB as an intended control measure for other outcomes measures that targeted physical function. The existence of this data set allows the opportunity for preliminary explorations of the stability of the CPIB over time in the context of non-speech interventions, as well as explorations of relationships between communicative participation and other measures targeting speech, cognition, and broader physical function. The research questions for this paper are:

1. What are the correlations between CPIB scores and outcome measures of activities of daily living (ADL), depression, cognition, and physical function respectively at the pre-intervention time point?
2. Do sub-groups of participants based on severity of CPIB scores differ on demographic or other measures?
3. A. Did CPIB scores change for the group as a whole after individuals with PD participated in a tandem cycling exercise program?

   B. Are there trends and/or common characteristics among the sub-groups of participants identified in question 2 in terms of whether or not their CPIB scores changed after the tandem cycling intervention?

   C. Are there trends and/or common characteristics among sub-groups of participants who reported improved communicative participation, deteriorating communicative participation, or no change in communicative participation during the tandem cycling program?
4. In a sub-group of participants for whom data are available, what is the association between CPIB scores and speech intelligibility as measured by the SIT for time point 1?

Methods

As stated above, the current study is a retrospective analysis of data gathered through the tandem cycling exercise program developed and implemented by McGough and colleagues (McGough et al., 2016). The cycling program consisted of sessions that were 60 minutes in length, three times per week for 10 weeks. From the front seat of the tandem bicycle, the cycling partner (who was a physically fit typical adult volunteer) set the pace, shifted the gears, and provided encouragement for the rider with PD. Pre- and post-program measures were collected and these measures were used for analysis to answer the current study's research questions. Each measure will be addressed in more detail below. Please see original study for further details about equipment and specific training parameters.

Participants

Adults with a diagnosis of PD (n=41) were recruited to participate in the community-based tandem cycling study. Inclusion criteria included a diagnosis of PD, age 45 to 75 years, able to walk 100 m (assistive device allowed), and physician approval. Exclusion criteria included a serious cardiac or pulmonary condition, diabetes mellitus, musculoskeletal contraindications, or a history of central nervous system disease other than PD. The University of Washington Institutional Review Board approved all study procedures. All participants provided written, informed consent. Participants were recruited through newsletter and website postings by local Parkinson disease organizations, and through the Washington State Parkinson Disease Registry. All eligible individuals were enrolled, and the 10-week program was offered 3 times per year from January 2012 through March 2014. The retention rate for participants was 100% (n=41) indicating that all participants completed the program.

Outcome Measures

In order to answer the specific research questions for the current study, this section will describe the different outcome measures and instruments that were used in the tandem cycling study. Among the measures collected for the larger study, this project will focus on the CPIB, the Sentence Intelligibility Test (SIT), Speech Usage, the Unified Parkinson Disease Rating Scale (UPDRS), the Parkinson Disease Questionnaire (PDQ-39), the Geriatric Depression Scale (GDS), the Montreal Cognitive Assessment (MoCA), Five Time Sit to Stand (FTSTS), and Timed Up and Go (TUG). Assessments were performed within one week before and one week after the 10-week tandem cycling program. An overview of purpose, development, and scoring will be addressed for each.

Communicative Participation Item Bank. As described above, the CPIB was developed as a patient-reported measure of communicative participation. In the current study, participants were given the 10-item short form of the CPIB in which they were asked to rate how much their condition (e.g., speech, health, or environmental condition) interfered in a variety of communication settings. Sample questions include “Does your condition interfere with talking with people you know?” and “Does your condition interfere with asking questions in a conversation?” For each question, there are four response choices: ‘not at all,’ ‘a little,’ ‘quite a bit,’ and ‘very much’, with scores reported in T-scores (mean = 50, SD = 10) or logits. Higher scores are more favorable.

Speech Intelligibility Test. The Sentence Intelligibility Test (SIT) has been used to measure the dysarthria severity of participants (Yorkston et al., 1996). The SIT program generates random sentence samples from a pool of 1,100 sentences (100 sentences of each length ranging from five to 15 words). The participant is recorded reading the sentences in a quiet room. To record the speech samples, participants wore a head-mounted AKG C520 microphone with the microphone positioned at the side of the mouth at a 2 cm mouth-to-microphone distance. The sound signal passed through an MTrackPlus M-Audio Interface before being recorded on a Lenovo Thinkpad T430s laptop using Audacity, an open-source recording software package. In the current study, voice recordings were obtained for a subset of participants (n=23). Due to feasibility issues, several recordings could not be used. In the end, SIT samples were available for 15 participants which are included in the final analysis in question 4.

To analyze the SIT sentences, naïve listeners were recruited to transcribe the speech samples. Inclusion criteria for the listeners included passing a hearing screening, and exclusion criteria included any extent of experience with listening to dysarthric speech (e.g., any SLP and second year graduate students). Raters were recruited through the University of Washington Speech & Hearing undergraduate and graduate programs. Raters were brought to a quiet room individually where their hearing was assessed and they were placed at a computer with sound cancelling headphones. The recorded SIT sentences were presented randomly by a custom-made software program (Ruby on Rails, www.rubyonrailsorg). Raters then followed prompts from the software to listen to each sample presented and type what they understood. Raters could listen to each sample a maximum of two times. Three listeners transcribed each sample. Once each rater listened to all the samples, lab staff exported all results into an excel spreadsheet. The primary author compared each transcript to the original sentence and scored the number of words transcribed correctly with a final intelligibility score for each speaker representing the average percent intelligible words across the three listeners. To assess reliability of scoring, 65% of the transcriptions were scored a second time by three University of Washington graduate students.

The primary author compared the two scores. Approximately 4% of the total sentences scored contained discrepancies which the primary author resolved.

Levels of Speech Usage. The Levels of Speech Usage is a scale developed to describe and code the speech usage of participants and was designed to be applicable across a range of communication disorders and life situations (Baylor, Yorkston, Eadie, Miller, & Amtmann, 2008). This scale is administered by having the participant think of how they have typically used their speech over the year prior to the test administration and are then asked to read descriptions for the different categories and choose the one that best describes them. Categories include "undemanding", "Intermittent", "Routine", "Extensive", and "Extraordinary".

Unified Parkinson's Disease Rating Scale. The UPDRS is a scale that was developed to incorporate elements from existing scales to provide a comprehensive, but efficient and flexible means to monitor PD-related disability and impairment. The original scale was critiqued in 2001 by the Movement Disorders Society (MDS) and in 2008 a revised version (MDS-UPDRS) was released with all of its psychometric testing results (Goetz et al., 2008; Movement Disorder Society Task Force on Rating Scales for Parkinson's Disease, 2003). The scale has four components, namely, Part I: *Non-motor experiences of daily living;* Part II: *Motor experiences of daily living;* Part III *Motor examination*; Part IV: *Motor Complications*. Each question within the scale is anchored with five responses that are linked to commonly accepted clinical terms: 0 = normal, 1 = slight, 2 = mild, 3 = moderate, 4 = severe. For the current study, the total score for the subscale Part II: Motor Experiences of Daily Living (self-report) is included as well as scores from individual items from the subscale selected by the research team. These included the self-reported items for speech severity, saliva, chewing/swallowing, eating tasks (e.g., handling utensils), handwriting, hobbies, and tremor. These items were all chosen to examine correlations between these patient-reported measures of physical function and difficulties in activities of daily living with the CPIB. Higher scores are less favorable.

Parkinson's Disease Questionnaire. The PDQ-39 is a disease-specific quality of life instrument that was designed with the purpose of being a tool that could be completed independently by the person with PD and could be included in the evaluation process in conjunction with other measures (Jenkinson, Fitzpatrick, Peto, Greenhall, & Hyman, 1997). The PDQ-39 was developed based on interviews and large-scale surveys, and contains eight dimensions: mobility, activities of daily living, emotional well-being, stigma, social support, cognition, communication, and bodily discomfort. Scores from the eight domains can be combined into a single index called the Parkinson's Disease Summary Index (PSDI). The dimension scores and the PSDI are reported on a scale of 0 – 100, with 0 being perfect health and 100 being the worst health.

Geriatric Depression Scale. The GDS is a patient-reported instrument developed for the use of assessing depression in older individuals. Several analyses have been done since its inception and have demonstrated its validity and reliability (Montorio & Izal, 1996; Yesavage et al., 1982). The GDS currently has a short-form with 15 items asking about how the person has felt over the week prior. Sample questions include "Are you basically satisfied with your life?" and "Do you often feel helpless?" and are answered either "yes" or "no." One point is awarded for each answer indicating depression. Higher scores are less favorable. A score of 0 to 5 is considered normal, and a score greater than 5 indicates depression. Although this measure was used as a continuous variable in the primary study, binary scoring was used for the current analyses as that is the recommended interpretation for this instrument.

Montreal Cognitive Assessment. The MoCA was developed as a tool to screen people who presented with mild cognitive complaints and were performing normally on other mental status exams (Nasreddine et al., 2005). The domains for the test were derived from commonly encountered characteristics of mild cognitive impairment (MCI). A trained person (speech-language pathologist or others) administers the assessment which includes tasks that screen visuospatial skills (e.g., trail-making test, three-dimensional cube copy and clock-drawing), general naming, memory, attention, language, and orientation. Psychometric tests revealed that the MoCA was both sensitive and specific in diagnoses of MCI and/or Alzheimer's disease (Nasreddine et al., 2005; Smith, Gildeh, & Holmes, 2007). Items correct are summed to give a final score between 0 and 30. Scores of 26 and above are considered normal. As with the GDS, this measure was used as a continuous variable in the primary study. However, binary scoring of presence versus absence of MCI was used for the current analysis as that is the recommended format for interpreting the instrument.

Gait Speed. Quantitative spatiotemporal gait measures were collected with the GAITRite Walkway System (MAP/CIR Inc, Havertown, Pennsylvania), a portable, instrumented mat that forms a 4.3-meter (m) walkway with pressure sensors that detect foot contacts. To ensure that steady-state walking was attained, participants started 2m before the edge of the mat and continued walking 2m beyond the mat. Gait speed (meteres/second) was averaged across 4 trials of usual pace walking, and again across 4 trials of fast pace walking. Good reliability of GAITRite measures has been reported for in older adults with PD (Nelson et al., 2002). Higher gait speeds are more favorable.

Five Times Sit to Stand. The FTSTS is a representation of lower limb muscle strength and can be useful in quantifying functional change of transitional movements. Participants are to sit in a straight-backed chair with a solid seat that is 16” high. They are to sit on the chair with arms folded across their chest and are asked to stand up and sit down as quickly as possible 5 times, keeping their arms folded across their chest. Timing stops when the participant stands the fifth time. Research has shown that the inability to rise from a chair five times in less than 13.6 seconds is associated with increased disability and morbidity (Guralnik et al., 2000). Another study suggested that the optimal cutoff time for performing the FTSST in predicting recurrent falls was 15 seconds (Buatois et al., 2008). In a study done specifically with people with PD, results indicated that times greater than 16 seconds indicated the risk of falls (Duncan, Leddy, & Earhart, 2011). For this study times are reported in seconds with longer times being less favorable.

Timed-up and Go. The TUG is an outcome measure that is used to assess mobility, balance, walking ability, and fall risk in older adults. After one practice trial, participants should sit in a straight-backed chair, sitting against the back of the chair. On the command “go”, the participant rises from the chair, walks 3 meters at a comfortable and safe pace, turns, and walks back to the chair and sits down. Timing begins at the instruction “go” and stops when the person is seated. Times greater than 9-13 seconds depending on the age of the person are considered at risk for falling (Bohannon, 2006). For this study times are reported in seconds with longer times being less favorable.

Results

Due to various reasons of feasibility, only a subset of speech data was available for the total 41 participants as not all speech measures could be collected at all time points for all participants. Therefore, the different analyses for the current study included different numbers of participants based on what data were available. Thus, for readability, participant demographics, statistical tests, and results are included with each research question based on number of participants. For a detailed breakdown of sample size per research question, please see Appendix A.

Question 1

"What are the correlations between CPIB scores and outcome measures of activities of daily living (ADL), depression, overall cognition, and physical function respectively at the pre-intervention time point?"

Data from 32 of the 41 participants were available for analysis for this question. Demographic data for these 32 participants are available in Table 1. The majority of this sample was male (62.5%), with an average age of 63.6 years and an average time since diagnosis of PD of 4.5 years.

TABLE 1. Demographics of Participants for Question 1 (n=32)

		Results	
Demographic Variable		Mean (SD)	Range
Age		63.6 (6.9)	53-76
Years since Diagnosis		4.5 (4.5)	>1 - 14
Demographic Variable		Frequency	% (n=32)
Gender	Female	12	37.5
	Male	20	62.5

For this question, the associations between the CPIB and variables representing various aspects of physical, cognitive, and emotional function were explored. Pearson product-moment correlations were used to examine the associations between the CPIB and the variables of age, years since diagnoses, motor aspects of daily living, quality of life, lower extremity function, and functional mobility because the instruments used to measure these variables represented scale level instruments. Spearman correlations were used to examine the associations between the

CPIB and the variables of gender, depression, cognitive function, and different aspects of daily living, as the instruments used to measure these variables represented ordinal or nominal variables. Analyses were conducted with SPSS version 18.0. Descriptive results for instruments included in the study are summarized in Table 2 and analysis results are represented in Table 3 for the Pearson correlations and Table 4 for the Spearman correlations.

TABLE 2. Descriptive results for instruments included in the study

		Results	
Measure	Description	Mean (SD)	Range
CPIB	Measures self-reported interference with communicative participation; Scores reported in T-scores (mean=50-; standard deviation = 10). Higher scores are more favorable.	56.0 (10.7)	32.4 – 71.0
UPDRS	Measures PD-related disability and impairment. Total score for self-report Section II: Motor Aspects of Experiences of Daily Living (M-EDL) reported here, ranging from 0-65. Lower scores are more favorable.	9.39 (5.2)	1 – 20
PDQ-39	Self-report quality of life questionnaire for PD patients. Scores reported as total score ranging from 0-100 with lower scores being more favorable.	23.3 (18.4)	2 – 90
FTSTS	Measure of lower extremity function and fall risk; involves repeated sitting to standing performed quickly without upper extremity assistance; Scores reported here are seconds needed to complete task; lower times are more favorable.	12.4 (3)	8.3 – 20.4
GS: Usual Pace	Collected with GAITRite Walkway System to measure gait speed averaged over 4 trials of usual pace walk. Reported in meters/sec, thus, lower scores indicate slower speeds and are less favorable.	1.3 (0.2)	0.8 – 1.7
GS: Fast Pace	See GS Usual above; measured over 4 trials of fast pace walk.	1.8 (0.3)	1.1 – 2.3
TUG	A test of functional mobility; involves rising from a straight-backed chair, walking three meters, turning, walking back to the chair and sitting back down. Scores are time to complete task measured in seconds; lower scores are more favorable.	8.9 (1.9)	6 – 16.5

TABLE 2 (continued). Descriptive results for instruments included in the study

		Variable	Frequency	Percentage
MOCA	Screens for mild cognitive impairment (MCI); Total scores range from 0-30 with scores of 25 or lower considered to have MCI. Frequency of participants categorized with presence or absence of MCI reported.	MCI No MCI	6 26	18.8 81.3
GDS	Patient-reported instrument assessing presence of depression in older age; Total scores range from 0-15 and participants who score lower than 5 are not depressed. Frequency of participants categorized as depressed /not depressed reported.	Depressed Not Depressed	4 27	12.9 87.1
Speech Usage	Self-report scale that requires participants to place themselves in a category that best represents how they use their voice	Undemanding Intermittent Routine Extensive Extraordinary	3 15 11 1 1	9.7 48.4 35.5 3.2 3.2

Note. CPIB = Communicative Participation Item Bank, UPDRS = Unified Parkinson Disease Rating Scale, PDQ-39 = Parkinson's Disease Questionnaire, FTSTS = Five Time Sit-to-Stand, GS = Gait Speed, TUG = Timed Up and Go, MOCA = Montreal Cognitive Assessment, GDS = Geriatric Depression Scale; MCI – mild cognitive impairment

TABLE 3. Pearson correlations for the variables included in the study.

Variable	1	2	3	4	5	6	7	8	9
1. CPIB	-								
2. Age	.198	-							
3. Years since diagnoses	-.547*	-.105	-						
4. UPDRS	-.619*	-.077	.641*	-					
5. PDQ-39	-.697*	-.164	.563*	.715*	-				
6. Gait Speed Usual	-.061	-.409*	-.030	-.207	-.249	-			
7. Gait Speed Fast	-.004	-.369*	.352*	-.002	-.090	.599*	-		
8. TUG	-.337	-.376*	.091	.197	.320	-.391*	-.542*	-	
9. FTSTS	-.095	.348	.001	.184	.186	-.636*	-.499*	.654*	-

Note. CPIB = Communicative Participation Item Bank, UPDRS = Unified Parkinson Disease Rating Scale, PDQ-39 = Parkinson's Disease Questionnaire, FTSTS = Five Time Sit-to-Stand, TUG = Timed Up and Go, *Significant at $p \leq .05$.

TABLE 4. Spearman correlations for the variables included in the study.

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. CPIB	-											
2. Gender	-.340	-										
3. GDS	.383	-.108	-									
4. MOCA	.296	-.207	.093	-								
5. Speech Usage	.039	-.250	-.223	-.128	-							
6. UPDRS: Speech	-.554*	-.316	-.138	.031	-.143	-						
7. UPDRS: Saliva	-.330	.092	.044	.017	-.181	.249	-					
8. UPDRS: Swallowing	-.489*	.200	-.007	.105	-.175	.251	.416*	-				
9. UPDRS: Eating	-.430*	.208	-.229	.168	-.137	.574*	.208	.172	-			
10. UPDRS: Handwriting	-.253	.224	-.089	.349	-.016	.225	.362	.404	.331	-		
11. UPDRS: Hobbies	-.119	-.021	-.200	.337	-.266	-.088	.478*	.257	.029	.458*	-	
12. UPDRS: Tremor	-.773*	.334	-.423*	-.289	-.042	.574*	.2567	.350	.317	.056	.060	-

Note. CPIB = Communicative Participation Item Bank, GDS = Geriatric Depression, MOCA = Montreal Cognitive Assessment, Scale; MCI – mild cognitive impairment, UPDRS: Unified Parkinson's Disease Rating Scale. UPDRS items analyzed here represent selected items from the self-report ADL portion of the UPDRS.

Strong correlations were observed between the CPIB and the variables of self-reported tremor (-.773), quality of life (-.697), and self-reported functioning in overall activities of daily living (-.619). These scores are interpreted as better communicative participation being associated with less tremor, better quality of life, and less severe PD symptoms. Moderate correlations were observed between the CPIB and years since diagnoses (-.547); and the self-reported variables of speech severity (-.554), chewing and swallowing difficulties (-.489), and eating tasks (i.e., handling food and using eating utensils) (-.430). These scores are interpreted as better communicative participation being associated with shorter time since diagnosis of PD, and less severe speech, chewing, swallowing, and eating difficulties. All of these strong and moderate correlations were significant at the p<.05 level. Some of the lowest correlations with the CPIB were the measures of physical function including usual gait speed (-.061), fast gait speed (-.004) and lower extremity function and fall risk (-.095). The correlation between the CPIB and self-rated speech usage was also very low (.039). It is possible that restriction of range might account for this low correlation because the majority of participants fell into only two of the five speech usage categories (see Table 2).

Question 2

"Do sub-groups of participants based on severity of CPIB scores differ on demographic or other measures?"

For this question, pre-intervention time-point CPIB scores from the 32 participants from Question 1 were visually analyzed. Subgroups were determined based on natural groupings of participants' scores, with proposed groupings reviewed by the research team. The grouping endorsed by all team members is shown in Figure 1 (for ease of reading, all figures for this question are placed at the end of the text for Question 2). This analysis resulted in three subgroups with high, medium, and low CPIB scores (see Table 5 for CPIB descriptive statistics of each subgroup).

TABLE 5. Mean and standard deviation for CPIB Scores for three CPIB Subgroups at the pre-intervention time point

	Results	
Subgroups (n=32)	Mean (SD)	Range
High CPIB Scores (n=10)	67.67 (3.04)	64.2 - 71
Medium CPIB Scores (n=13)	56.79 (3.19)	51.5 - 60.6
Low CPIB Scores (n=9)	42.02 (4.87)	32.4 - 49

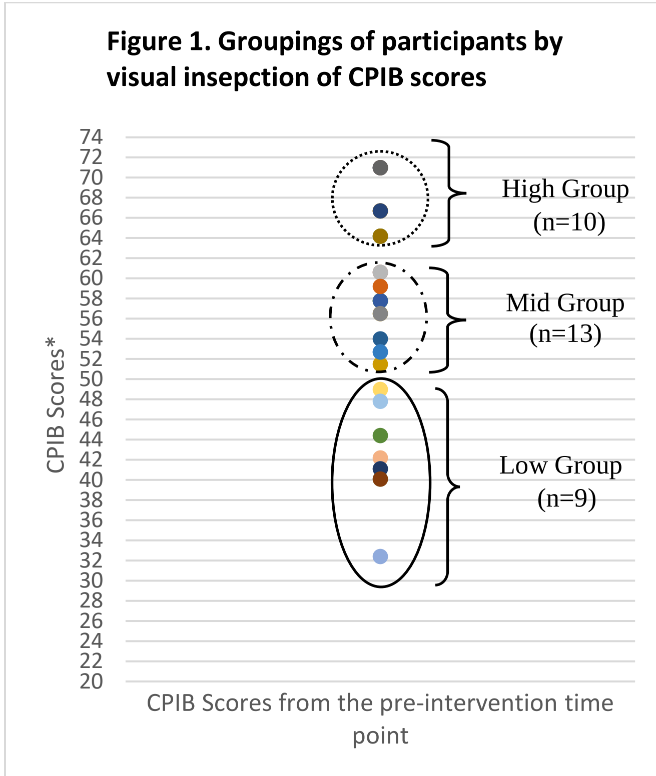
The high group consisted of participants more than one standard deviation above the mean of the calibration sample (T Score = 50; SD = 10). The mid group consisted of participants with scores between the mean and approximately 1 SD above the mean. Several participants whose scores were slightly above 1 SD were included in the mid CPIB group based on the visual analysis approved by the research team. The low group consisted of participants with scores below the mean. In order to examine characteristics of the subgroups, the variables that showed strong correlations with CPIB scores from Question 1, along with demographic data, were included in the analysis. These variables included self-reported tremor severity, QOL, self-reported overall functioning in ADLs, as well as specific self-reported variables of speech severity, difficulty with eating tasks (i.e., handling food and using utensils), and chewing/ swallowing difficulties. Demographic variables included were gender, age, and years since diagnosis. Due to small group sizes, data are presented graphically for visual analysis and descriptive summaries, but inferential tests were not conducted.

Results suggest that the low CPIB group (indicating more problems with participation) may differ from the other two groups. The low CPIB group had a higher proportion of males (89% compared to 46-50% in the other CPIB groups; Figure 2). Although the age of participants in the low CPIB group did not appear different from the other two groups based on visual inspection (Figure 3), participants in the low CPIB group had an average time since diagnosis of over eight years whereas the other two groups had a time since diagnosis ranging from two to three years (Figure 4). The low CPIB group participants reported more difficulties with ADLs (UPDRS score of 15.6 compared to 7.1-7.3 in the other CPIB groups with high scores being less favorable; Figure 5). Participants in the low CPIB group appeared to have lower QOL ratings (PDQ-39 score of 46 compared to 13.7-16.7 in the other CPIB groups with higher scores being less favorable; Figure 6). The low CPIB group had a higher proportion of participants that reported moderate difficulty with eating tasks (75%) with zero participants reporting no difficulty (Figure 7). In contrast, the high and mid CPIB groups had a higher percentage of participants reporting no difficulty whatsoever (15-30%) and a lower percentage of self-reported difficulty with eating tasks within each response category (8-30% between response categories). The low CPIB group had comparatively more participants reporting difficulty with tremor (13-50% reporting difficulties compared to 85-100% reporting *no* difficulties in the other groups; Figure 8). Finally, the low CPIB group reported more difficulty with chewing and swallowing

(25-38% reporting difficulties compared to 69-100% reporting *no* difficulties in the other groups Figure 9).

The high and mid CPIB groups not only showed more favorable results within most of the variables than the low CPIB group, but the high and mid groups also appeared to have comparable results to each other in relation to the variables of gender, years since diagnosis, and overall self-reported difficulty with ADLs, tremor, chewing and swallowing. The variables of chewing/swallowing, and tremor both had similar distributions of severity within the high and mid CPIB groups with 100% of participants in the high CPIB group reporting no effect from either variable.

The distribution of participants across the speech severity range appeared to differ somewhat between CPIB groups (Figure 10). For example, 50% of participants in the high CPIB group reported normal speech, whereas only 23% of participants in the Mid CPIB group, and no participants in the low CPIB group self-reported normal speech. The most commonly endorsed speech severity category in the Mid CPIB group was “slight”, and the most commonly endorsed speech category in the Low group was “mild”. The low group was the only group to include any participants who endorsed the “moderate” speech category (25%).



Note. *T-Scores with 50 = mean of calibration sample; SD = 10; This visual representation contains participants with overlapping scores. For detailed scoring within groups, see Appendix B.

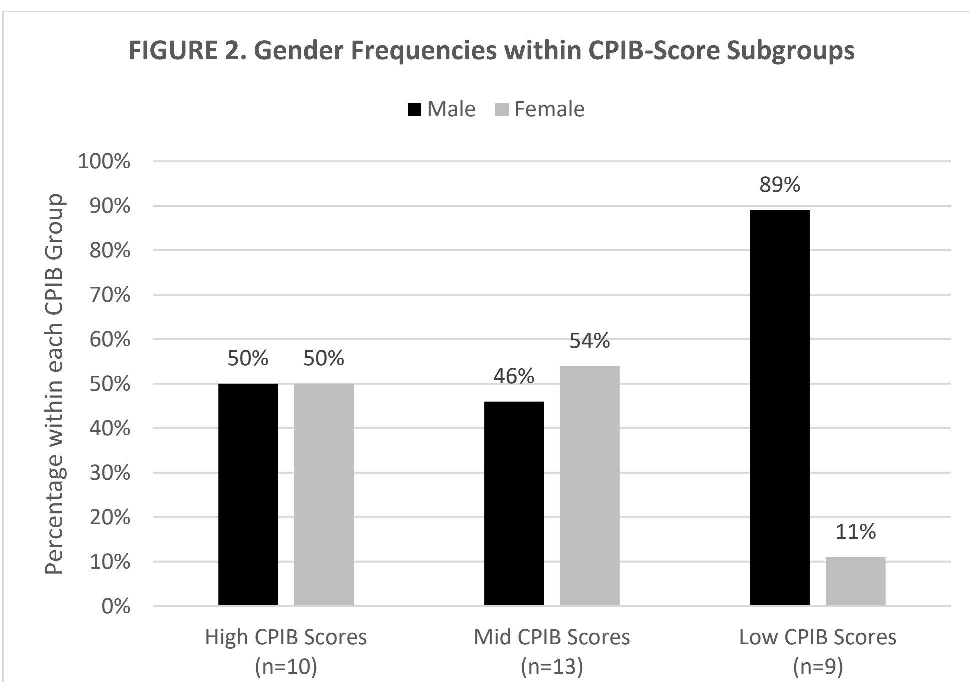


FIGURE 3. Age Mean and SD within CPIB Subgroups

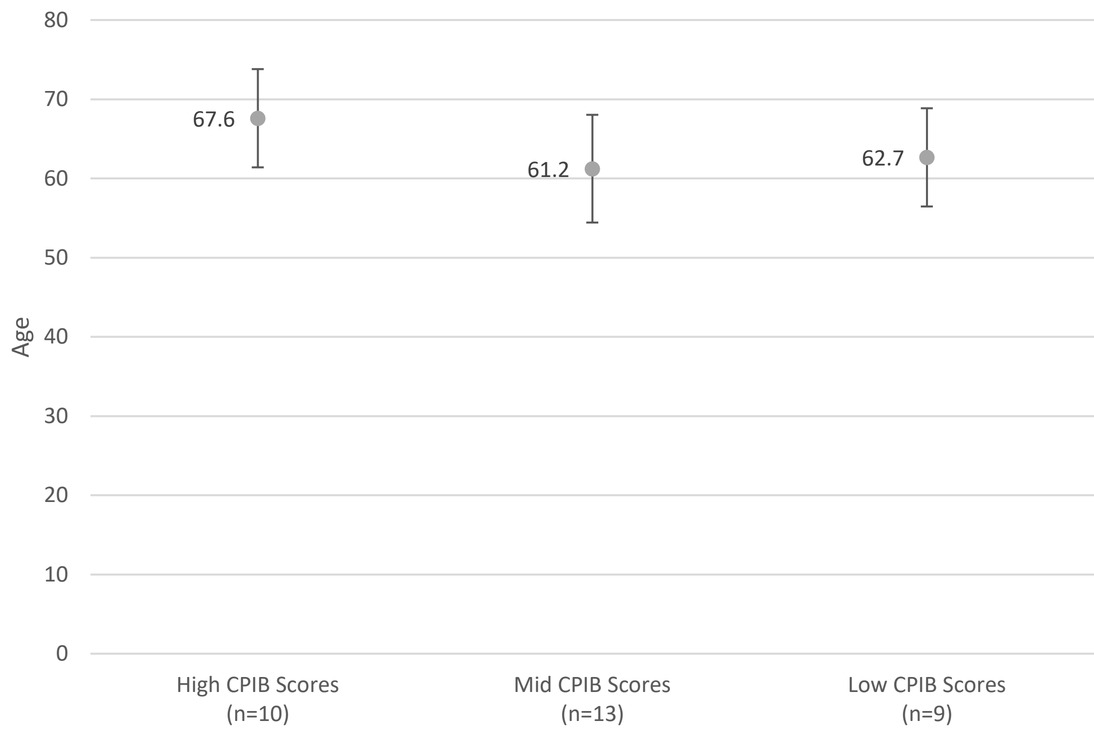
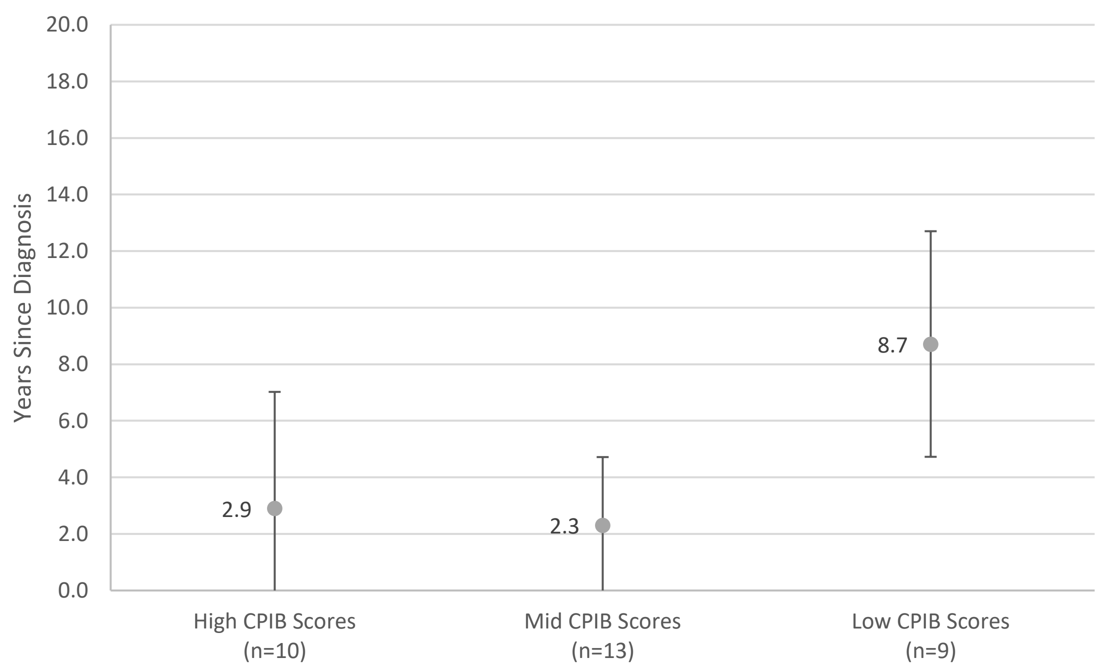


FIGURE 4. Years-Since-Diagnosis Mean and SD within CPIB Subgroups



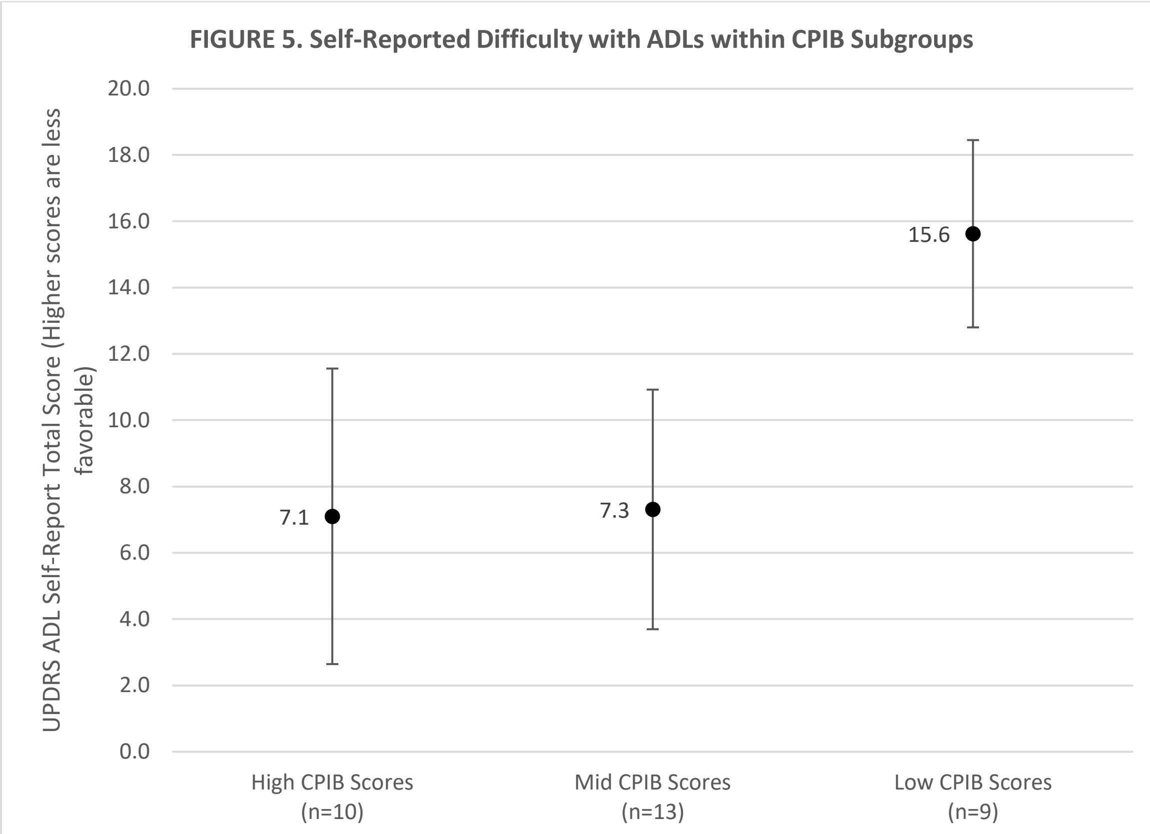


FIGURE 5. Self-Reported Difficulty with ADLs within CPIB Subgroups
UPDRS ADL Self-Report Total Score (Higher scores are less favorable)
20.0
18.0
16.0
14.0
12.0
10.0
8.0
6.0
4.0
2.0
0.0
7.1
7.3
15.6
High CPIB Scores (n=10)
Mid CPIB Scores (n=13)
Low CPIB Scores (n=9)

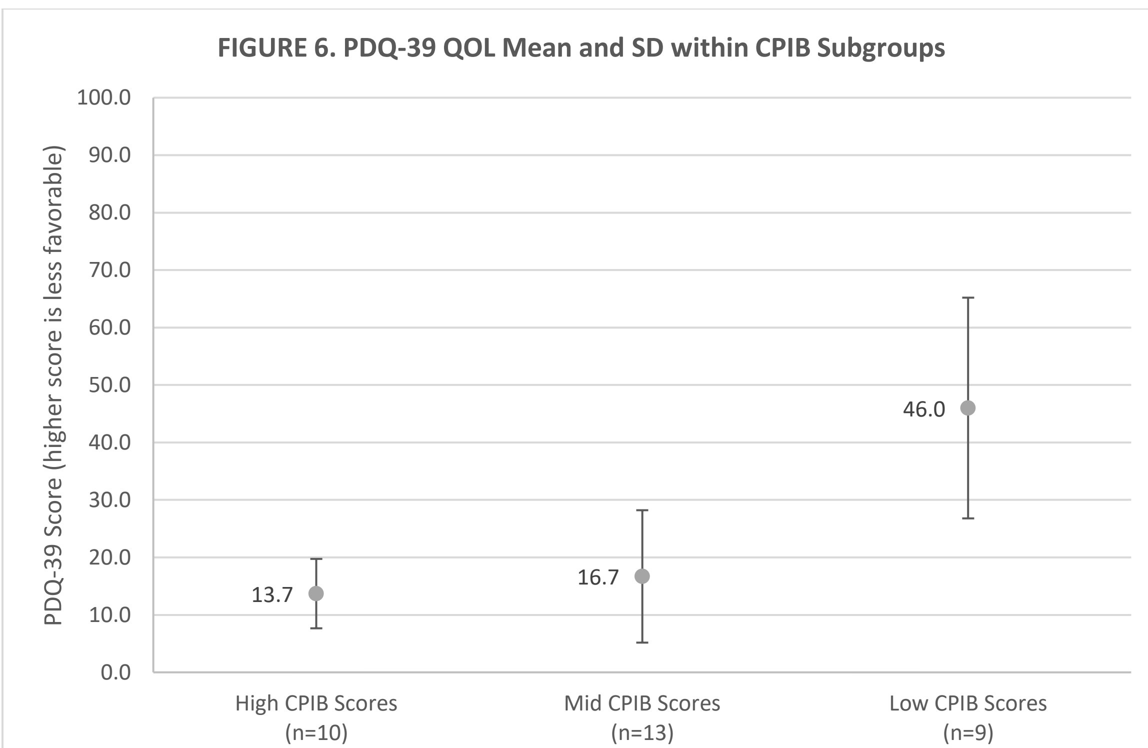


FIGURE 6. PDQ-39 QOL Mean and SD within CPIB Subgroups
PDQ-39 Score (higher score is less favorable)
100.0
90.0
80.0
70.0
60.0
50.0
40.0
30.0
20.0
10.0
0.0
13.7
16.7
46.0
High CPIB Scores (n=10)
Mid CPIB Scores (n=13)
Low CPIB Scores (n=9)

FIGURE 7. Self-Reported difficulty with Eating Tasks within CPIB Subgroups

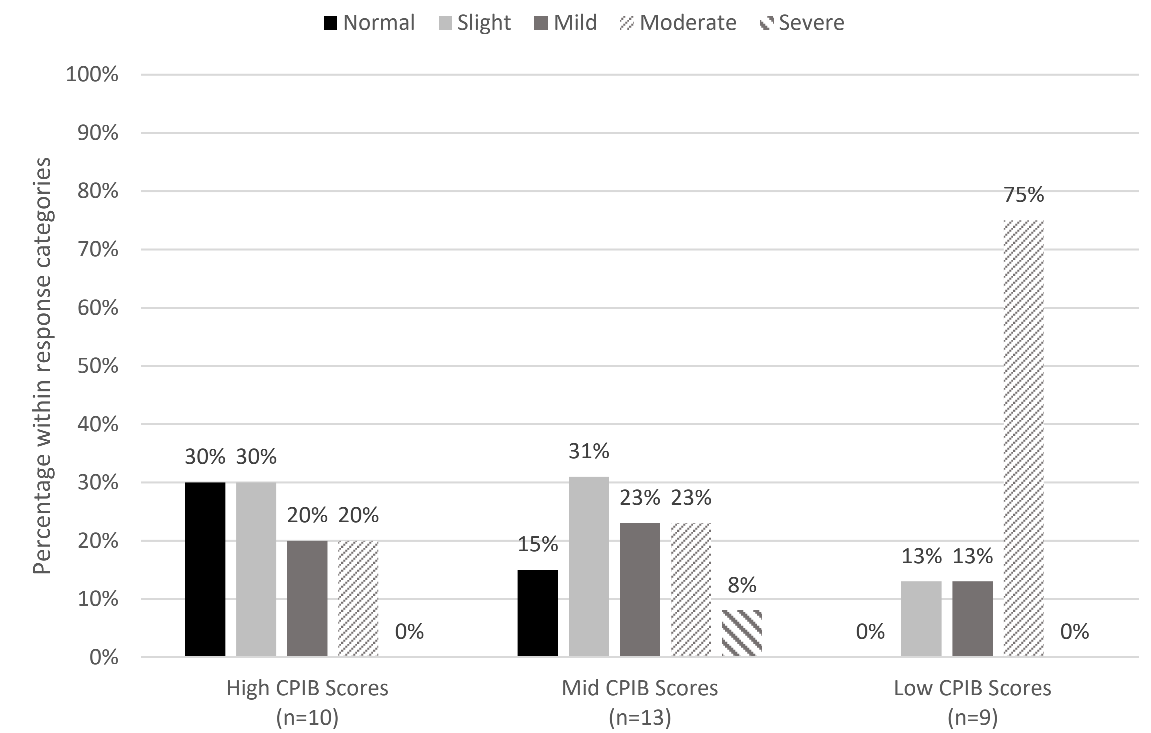
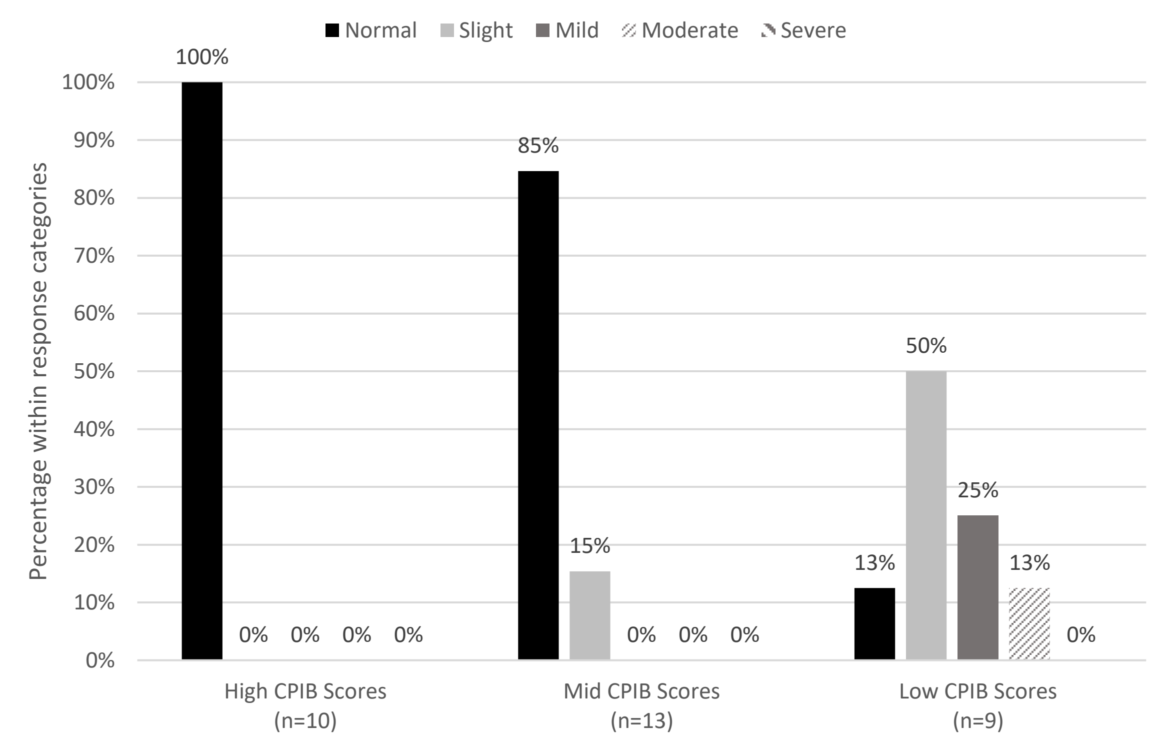


FIGURE 8. Self-Reported Tremor Severity within CPIB Subgroups



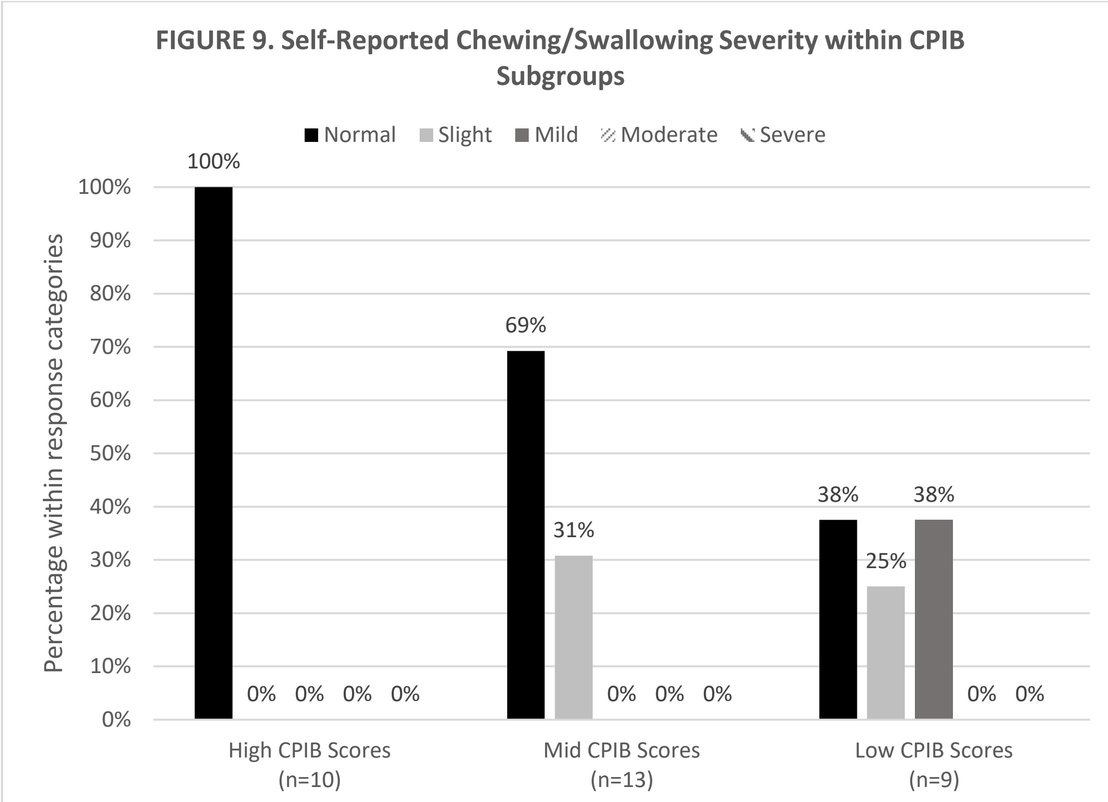


FIGURE 9. Self-Reported Chewing/Swallowing Severity within CPIB Subgroups
Normal
Slight
Mild
Moderate
Severe
Percentage within response categories
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
100%
0% 0% 0% 0%
69%
31%
0% 0% 0%
38%
25%
38%
0% 0%
High CPIB Scores (n=10)
Mid CPIB Scores (n=13)
Low CPIB Scores (n=9)

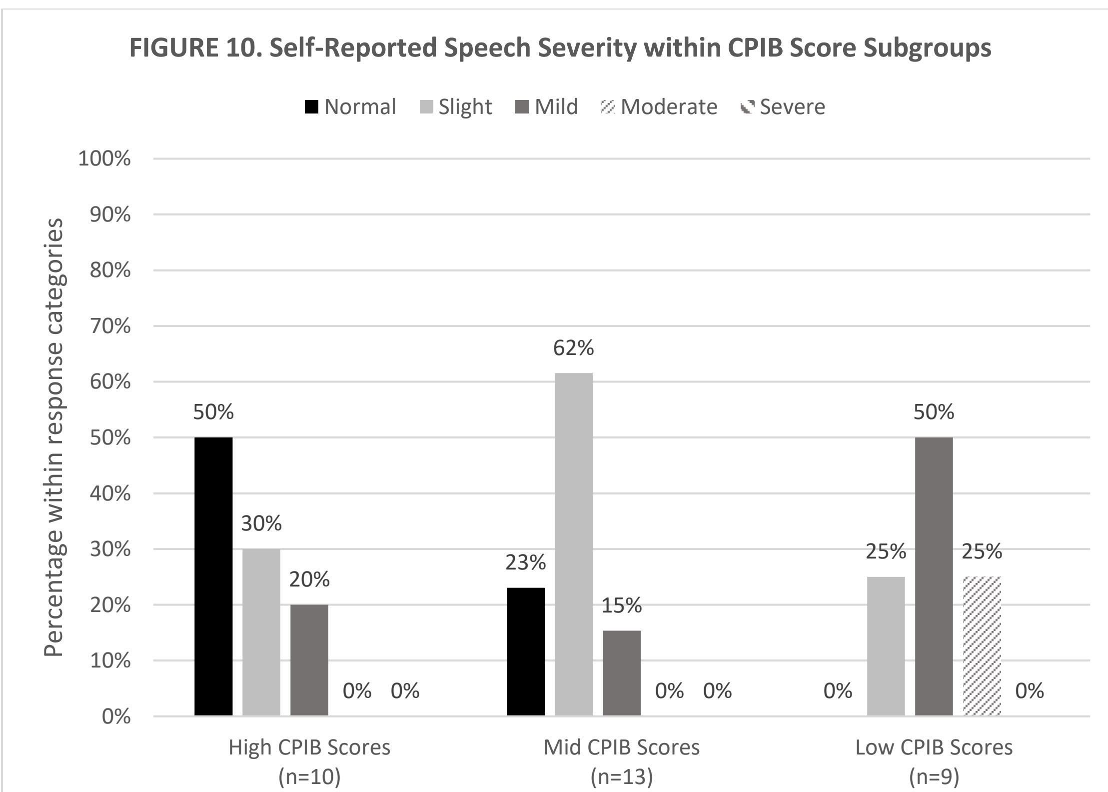


FIGURE 10. Self-Reported Speech Severity within CPIB Score Subgroups
Normal
Slight
Mild
Moderate
Severe
Percentage within response categories
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
50%
30%
20%
0% 0%
23%
62%
15%
0% 0%
0%
25%
50%
25%
0%
High CPIB Scores (n=10)
Mid CPIB Scores (n=13)
Low CPIB Scores (n=9)

Question 3

Questions 3A, 3B, and 3C address communicative participation over time by looking at CPIB scores before and after the tandem cycling intervention. Thus, only participants who had CPIB scores pre- and post-intervention were included. This resulted in data for 26 of the original 41 participants being included in these analyses. Demographic data for these 26 participants are available in Table 6. As with the larger group of 32 participants who had pre-intervention data available that were analyzed in questions 1 and 2, the majority of this portion of the sample were male (62%). However, these participants had an average age of 64 years and an average time since diagnosis of PD of 4.2 years.

TABLE 6. Demographic data of Participants for Question 3A-C (n=26)

		Results	
Demographic Variable		Mean (SD)	Range
Age		64 (7.2)	53-76
Years since Diagnosis		4.2 (4.5)	>1 - 14
Demographic Variable		Frequency	% (n=26)
Gender	Female	10	38
	Male	16	62

Question 3A: "Did CPIB scores change for the group as a whole after individuals with PD participated in a tandem cycling exercise program?"

For this question, the CPIB scores were analyzed using a paired samples *t*-test in SPSS Version 18. The mean of the CPIB scores prior to intervention was 56.5 (SD=10.7) and the mean after the cycling program was 55.8 (SD = 11.4). Overall, results suggest that there was no significant difference between CPIB scores before and after the tandem cycling intervention (n=26, p = .603).

Question 3B: "Are there trends and/or common characteristics among the sub-groups of participants identified in question 2 in terms of whether or not their CPIB scores changed after the tandem cycling intervention?"

For this question, the 26 participants with pre and post scores were examined according to the groups to which they were assigned in Question 2 in terms of showing low, mid, or high CPIB scores at the first time-point. Mean and SD for CPIB scores before and after intervention are reported for each group in Table 7. Due to the small sample size of each group, mean and SD were not considered to be as strong of a representation of trends as would be seen in larger sample sizes. Thus, visual analyses completed for individual participant trajectories are shown in Figure 11 for the CPIB group with pre-intervention scores in the high range, Figure 12 for the CPIB group with pre-intervention scores in the mid-range, and Figure 13 for the CPIB group with pre-intervention scores in the low range (again please refer to the end of the text in this section for all figures related to this question).

TABLE 7. Mean and standard deviation for CPIB Scores for the three CPIB Subgroups based on CPIB scores at the pre-intervention time point

	Results	
	Pre	Post
Subgroups (n=26)	Mean (SD)	Mean (SD)
High CPIB Scores (n=8)	67.68 (2.93)	64.16 (6.35)
Medium CPIB Scores (n=12)	57.13 (3.06)	58.03 (6.38)
Low CPIB Scores (n=6)	40.21 (4.1)	40.35 (9.5)

The means of pre and post CPIB scores in the high group revealed a slight overall decline in self-reported communicative participation (Table 7). Inspection of individual participants (Figure 11) showed that the half of participants in this group did decline (50%). The participant with the largest decline of all participants was found in this group (71 pre to 55.3 post; 15.7 point difference) which also influenced the decline represented in the mean. The two participants who started with CPIB scores in the high group and showed improvement only improved by 2-4 points.

The mean of CPIB scores in the mid group revealed little difference overall pre to post (Table 7). However, visual analysis of individual scores revealed much wider variety in self-reported communicative participation scores pre to post (Figure 12). Over half of the mid group showed improvement (58%) and the biggest improvement of all participants was found in this group (57.8 pre to 66.7 post; 8.9 point difference).

The means of CPIB scores in the low group also suggests little change in self-reported communicative participation for these participants (Figure 13). However, the higher standard deviation suggests a wider range of scores post-intervention (Table 7). Of the participants who started in the low group, 50% of them showed a decline. The participant with the lowest CPIB score overall who was in this group was also among those who declined, thus resulting in the participant's post-intervention score being the lowest of all participants pre and post.

In summary, analyses of CPIB scores pre to post within the groups defined by high, mid, or low scores at the first time-point appeared to support the results of the paired *t*-test done in Question 3A. Means and SDs of each group revealed either slight decline or little change pre to post, and visual analysis of each group revealed no discernable pattern. While the group level statistics showed little change from pre to post, the visual inspection did reveal change for most participants. These changes were not evident in the group level statistics because the number of individual participants who improved was relatively equal to the number that declined, thus muting any meaningful change that may have occurred for individual participants when seen at the group level.

FIGURE 11. Individual Participant Trajectories within the group with high pre-intervention CPIB scores

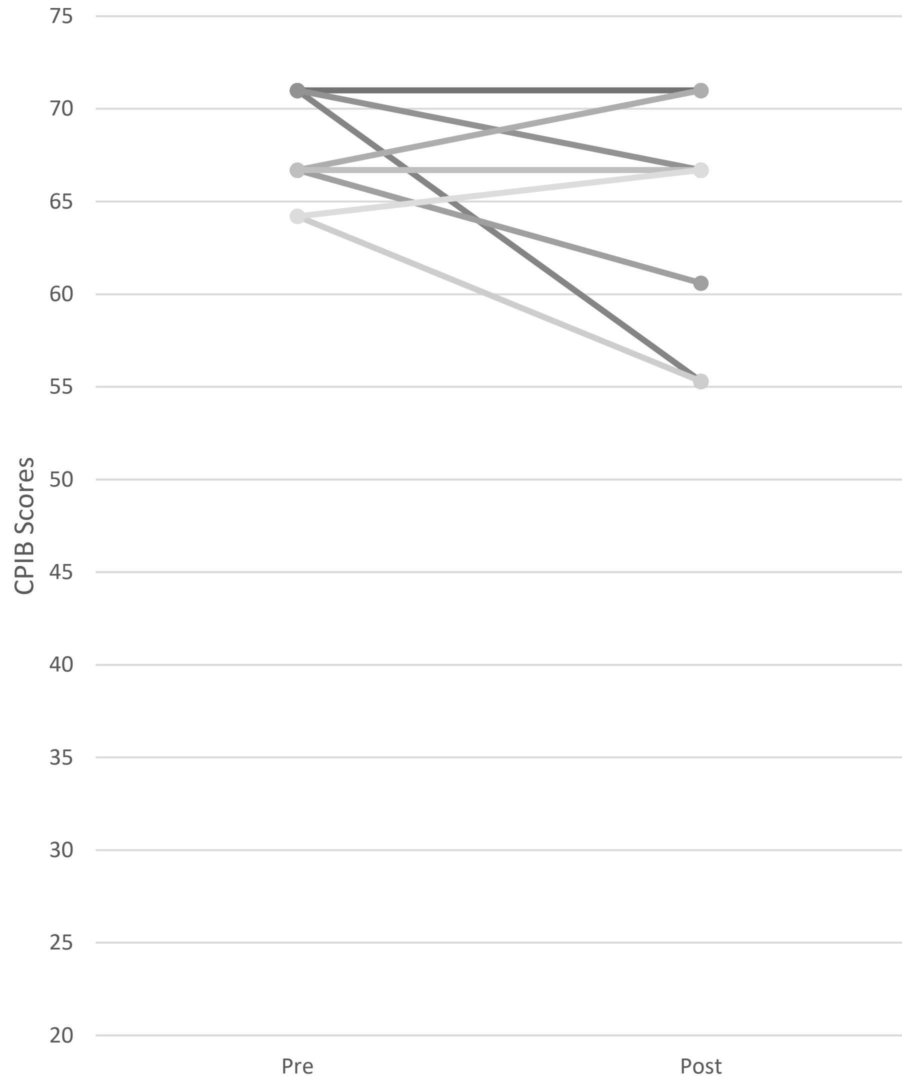


FIGURE 12. Individual Participant Trajectories within the group with mid pre-intervention CPIB scores

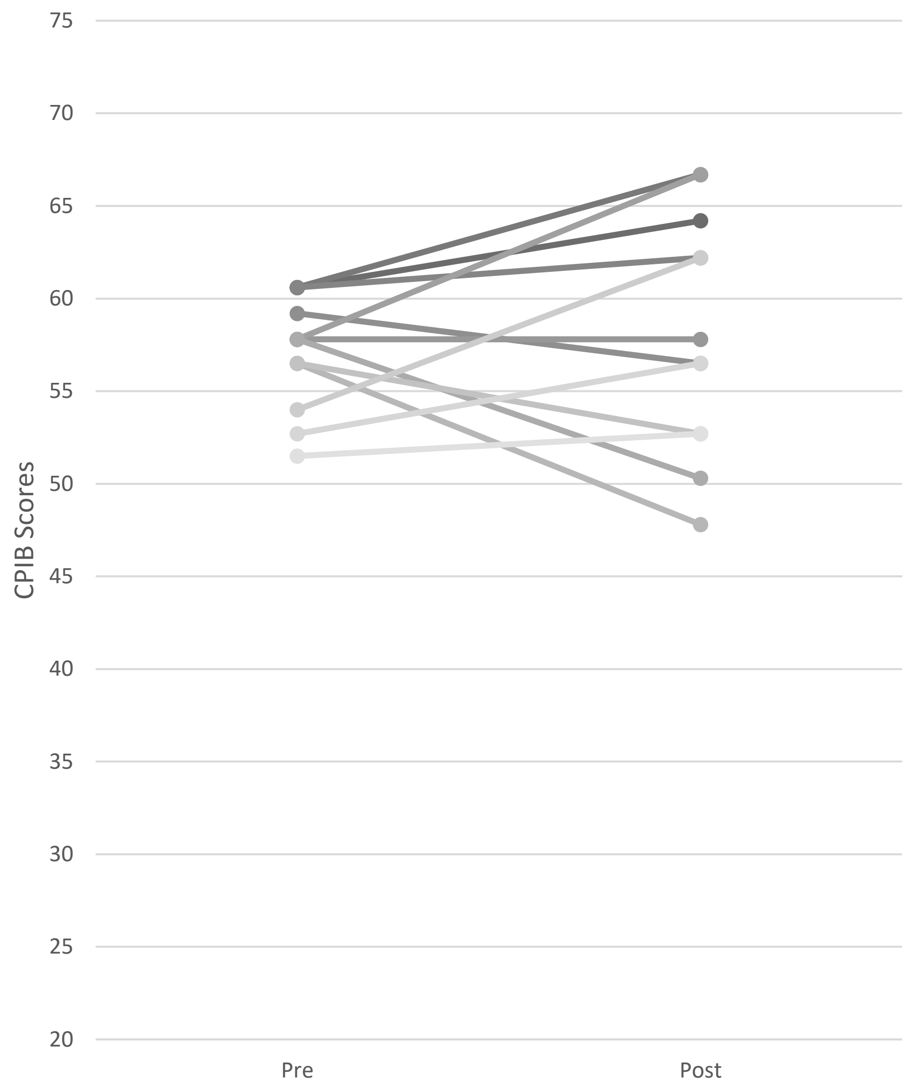
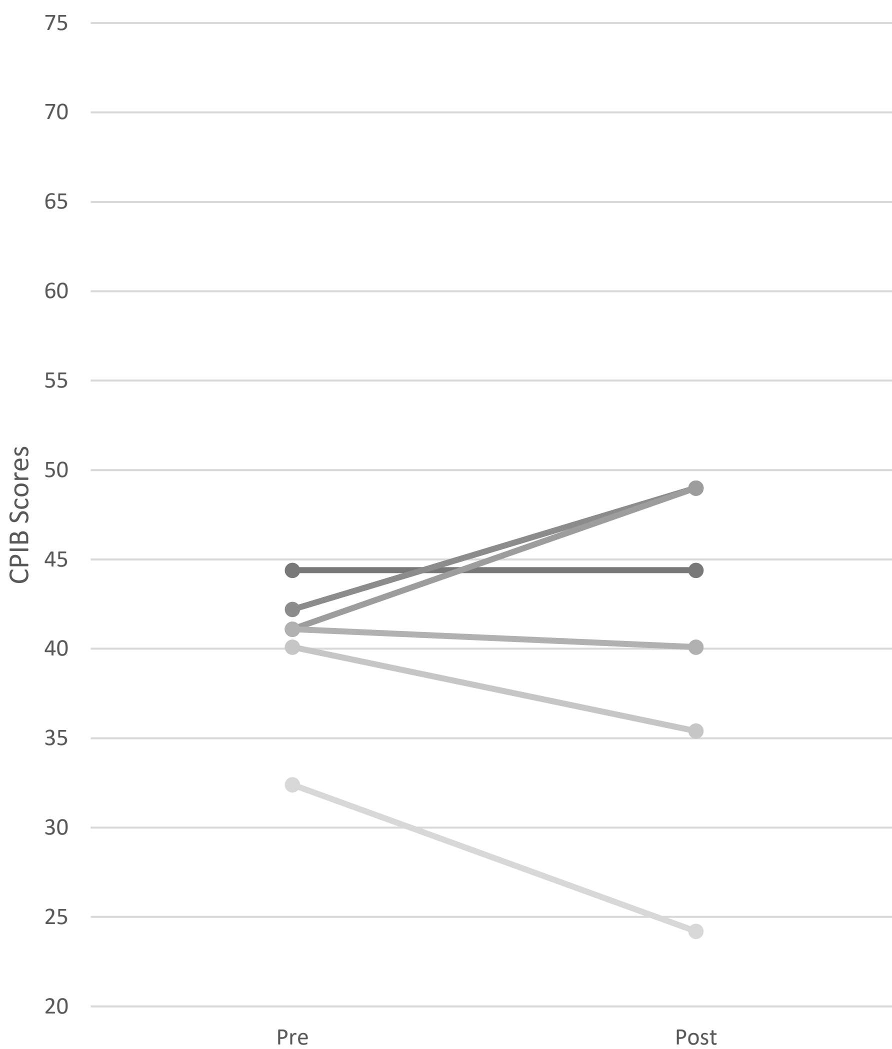


FIGURE 13. Individual Participant Trajectories within the group with low pre-intervention CPIB scores



Question 3C: "Are there trends and/or common characteristics among sub-groups of participants who reported improved communicative participation, deteriorating communicative participation, or no change in communicative participation during the tandem cycling program?"

For this question, the 26 participants were divided into different groups based on the direction of change in their CPIB scores pre to post. This was accomplished by placing participants whose scores improved by half of a standard deviation or more into the "Improved CPIB Scores" group (n=5), participants whose scores declined by half a standard deviation or more into the "Declined CPIB Scores" group (n=6), and the final group consisting of participants whose CPIB scores stayed within half of a standard deviation in either direction. This final group is referred to as the "Stable CPIB Scores" group (n=15). The same demographic variables and variables that showed strong associations with the CPIB in Question 2 were examined here. These variables include gender, age, years since diagnosis of PD, self-reported difficulty with ADLs, QOL, self-reported tremor severity, self-reported difficulty with eating tasks, self-reported difficulty with chewing/swallowing, and self-reported speech severity. Because one of the purposes of this study was to examine the relationship between communicative participation and physical function, the FTSTS – an outcome measure that reflects the variable of physical function – was added to this analysis as well.

Visual analysis of demographic data suggested that participants in the Improved CPIB Scores group had slightly more males (60%), the Stable CPIB Scores group had slightly more females (53%), and the Declined CPIB Scores group had 100% males (Figure 14; again, please refer to the end of the text in this section for all figures related to this question). Regarding age, results suggested participants in the Improved CPIB Scores group had a mean age of 60.2 years which was approximately 5 years younger than the mean of those in the Declined and Stable CPIB Scores groups (64.8 and 65; Figure15). Years since diagnosis showed variation in each group with the Improved CPIB Scores group showing a mean of 3.63 years, the Declined CPIB Scores group showing a mean time since diagnosis of 1.9 years, and the Stable CPIB Scores group showed a mean time since diagnosis of 5.3 years. However, SDs within both the Improved and the Stable CPIB Scores groups suggest considerable variation in time since diagnosis (Figure 16).

For each variable that used outcome measures with scale scores, means and SD of pre and post data were calculated using SPSS version 18 and were then displayed visually for comparison. These variables were the self-reported difficulty with ADLs, QOL, and physical function. Visual analysis of the self-reported ADL difficulty revealed improvement in all three groups (Figure 17). However, the improvements were slight, ranging 1-3 points difference pre to post across groups. Visual analysis of self-reported QOL revealed that those in the Improved CPIB Scores group also showed improvement in QOL, those in the Stable CPIB Scores group showed slightly worse QOL scores (from a mean of 17.8 to a mean of 19.3), and those whose CPIB scores declined showed no change at all (Figure 18). Visual analysis of the FTSTS revealed that participants in the Improved and Stable CPIB scores groups had overall improved times. Those in the Declined CPIB Scores group showed no change over time (Figure 19).

Variables that were measured with instruments that used ordinal data were also analyzed visually according to the percentage of responders within response categories pre to post. These variables are self-reported speech severity, self-reported chewing/swallowing difficulty, self-reported eating difficulty, and self-reported tremor severity.

Participants in the Improved CPIB Scores group had varying levels of self-reported speech severity at baseline, with the percentage of participants who reported normal speech increasing post-intervention (20% up to 40%; Figure 20). Those in the Stable CPIB Score group showed variable results in speech severity. Participants reporting no problem with speech remained unchanged in this group (27%). However, the number of responses in the “mild” category decreased post-intervention and appeared to split between “slight”, “moderate”, and “severe”. This indicates some improved while others declined, thus demonstrating the lack of a definite trend within the Stable CPIB Score group. The Declined CPIB Score group showed a small shift from “slight” responses to “mild”, thus suggesting more difficulty with speech post-intervention (Figure 20).

In analyzing the participants’ self-reported chewing/swallowing difficulty, the Improved CPIB Scores group revealed no change in responses pre to post, with the majority (80%) reporting having no difficulties with chewing/swallowing and the remaining (20%) reporting only slight difficulties (Figure 21). The participants in the Stable CPIB scores group had more difficulty chewing/swallowing post intervention as evidenced by a decrease in the number of participants reporting no problem and an increase in participants endorsing the “slight” category. Those in the Declined CPIB Scores group had less difficulty chewing/swallowing as evidenced by the number of responders who reported no problems increasing post-intervention (60% up to 80%; Figure 21).

For eating difficulties, the Improved CPIB Scores group had the same number of participants reporting no problem pre and post-intervention, but the number of participants who endorsed “slight” problems decreased (40% down to 20%) with an increase in the “mild” endorsement (0% to 20%). This suggests more difficulty in eating for the Improved CPIB Score group post-intervention (Figure 22). The Stable CPIB Scores group showed that participants reporting “mild” difficulty appeared to improve as evidenced by an increase in participants endorsing “slight” and “no problem” categories, while the number of responses within the “moderate” and “severe” categories remained unchanged. Those in the Declined CPIB Scores group had no participants that reported no difficulty with eating (0%), but overall the group showed improvement with a shift from responses in the “moderate” category to the “mild” category (Mild from 40% up to 80%). The number of participants with “slight” difficulties remained the same pre to post (20%; Figure 22).

Self-reported tremor severity analysis revealed over half (60%) of participants reporting no difficulties with tremor within the Improved CPIB Scores group (Figure 23) and this did not change pre to post. There was an overall improvement in tremor severity as the number of participants endorsing “slight” severity increased (20% up to 40%). The participants in the Stable CPIB scores group improved as evidenced by the increase in the number of participants who reported no problems with tremor (73% up to 87%). The number of participants endorsing “moderate” difficulty within this group stayed the same (7%; Figure 23). The Declined CPIB Scores group had 100% of responders reporting no trouble with tremor pre-intervention. This decreased to 80% reporting no trouble with 20% having worsened to “slight” difficulty (Figure 22).

Based on the visual analyses of the individual variables discussed above, the group of participants who showed improvement in their CPIB scores over time showed a trend towards improvement across the seven variables examined as evidenced by five of the seven variables revealing improved outcomes post-intervention. Chewing/swallowing did not show improvement, but was the variable in which 80% of participants reported no problem, and the group in which there was no change pre to post. Within this group of improved CPIB scores, eating was the only variable in which there were worse scores post-intervention, but these changes occurred only in the mild-moderate range and the number of participants reporting no problem stayed the same (20%).

The visual analysis of the group of participants whose CPIB scores were stable suggested overall variability in pre- to post-intervention outcomes across the seven variables examined. Out of the seven variables, only three showed improvement post-intervention (self-reported difficulty with ADLs, self-reported tremor severity, and physical function), two variables revealed worse outcomes (PDQ-39, and chewing/swallowing), and two variables did not have a strong shift in either direction (speech and eating). Such varying results indicate a lack of any specific trend within this CPIB group.

Finally, the visual analysis of the declining CPIB score group also revealed variability in pre to post intervention outcomes. Only two of the seven variables suggested improvement over time (self-reported difficulty with ADLs and self-reported chewing difficulty), three indicated worse outcomes (self-reported speech severity, self-reported eating difficulty, and tremor), and two variables showed no change (QOL and FTSTS). Such varying results indicate a lack of any specific trend within this CPIB group as well.

Overall, results suggest that those whose CPIB scores improved, tend to mirror said improvements in other variables. This parallel was not noted in the other two subgroups of participants. These results should also be interpreted with caution due to the small number of participants within each subgroup.

FIGURE 14. Gender within groups according to CPIB's direction of change

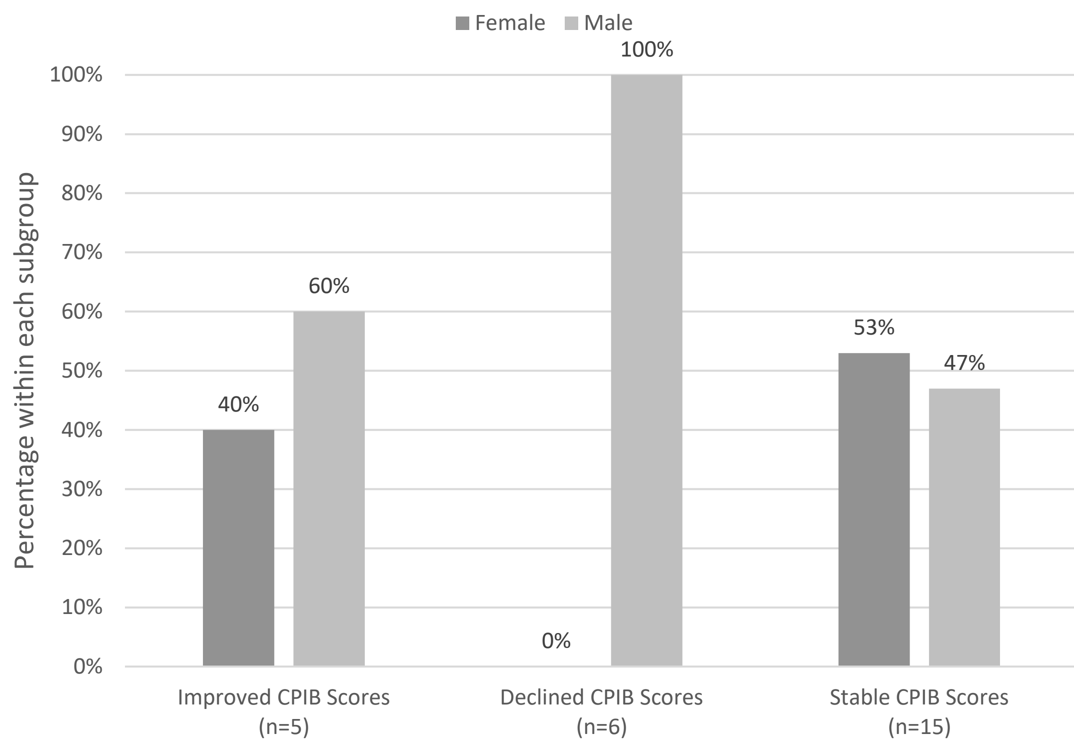
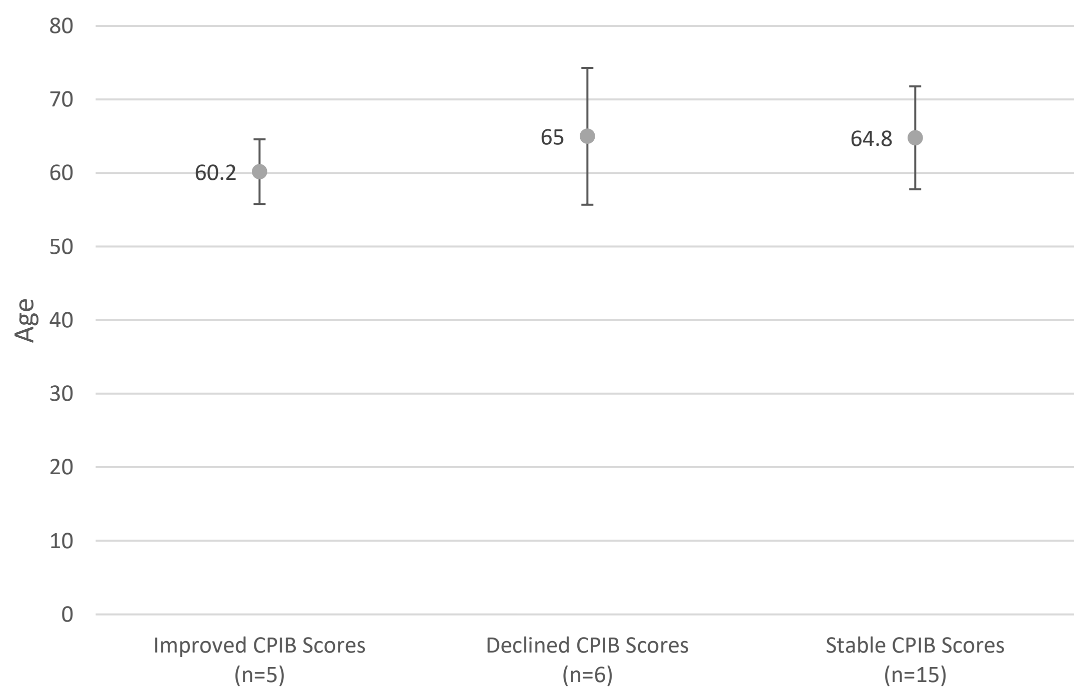


FIGURE 15. Meand and SD of Age according to CPIB score's direction of change



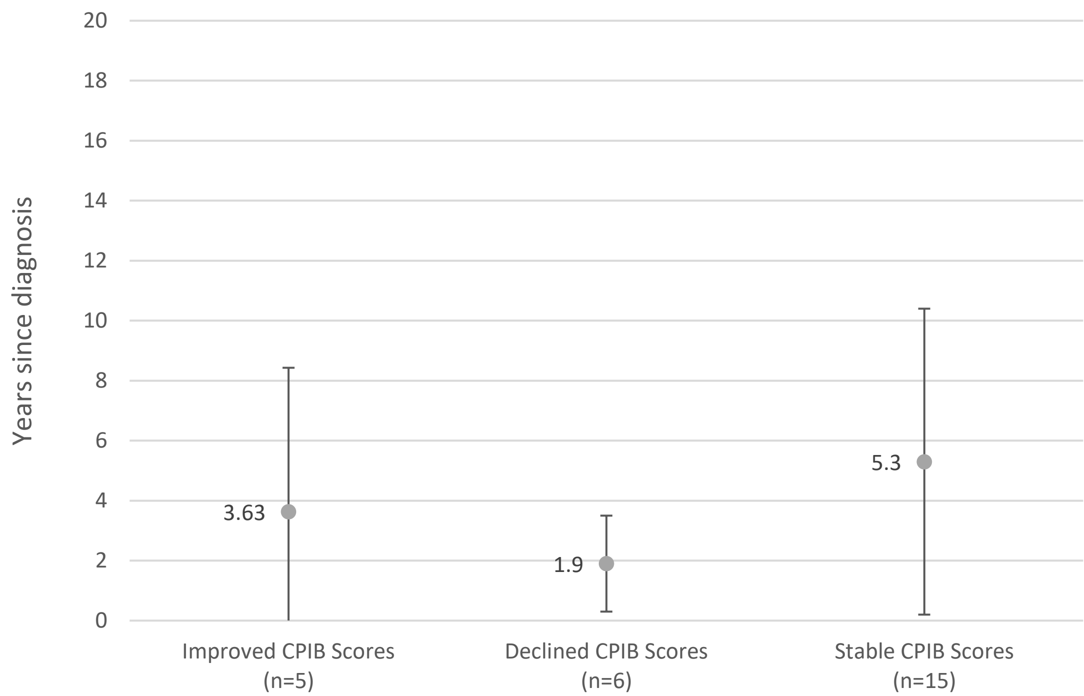


FIGURE 16. Years since diagnosis Mean and SD according to CPIB score's direction of change

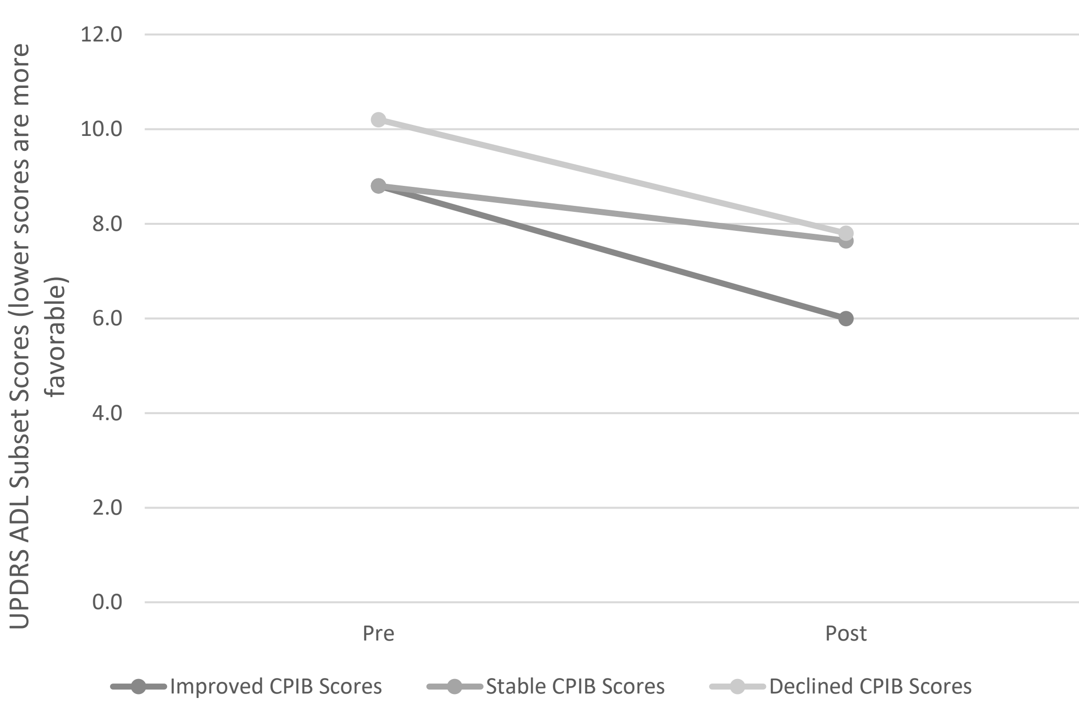


FIGURE 17. Comparison of UPDRS Subscale Scores pre to post according to CPIB score's direction of change

FIGURE 18. Comparison of PDQ-39 Scores pre to post according to CPIB score's direction of change

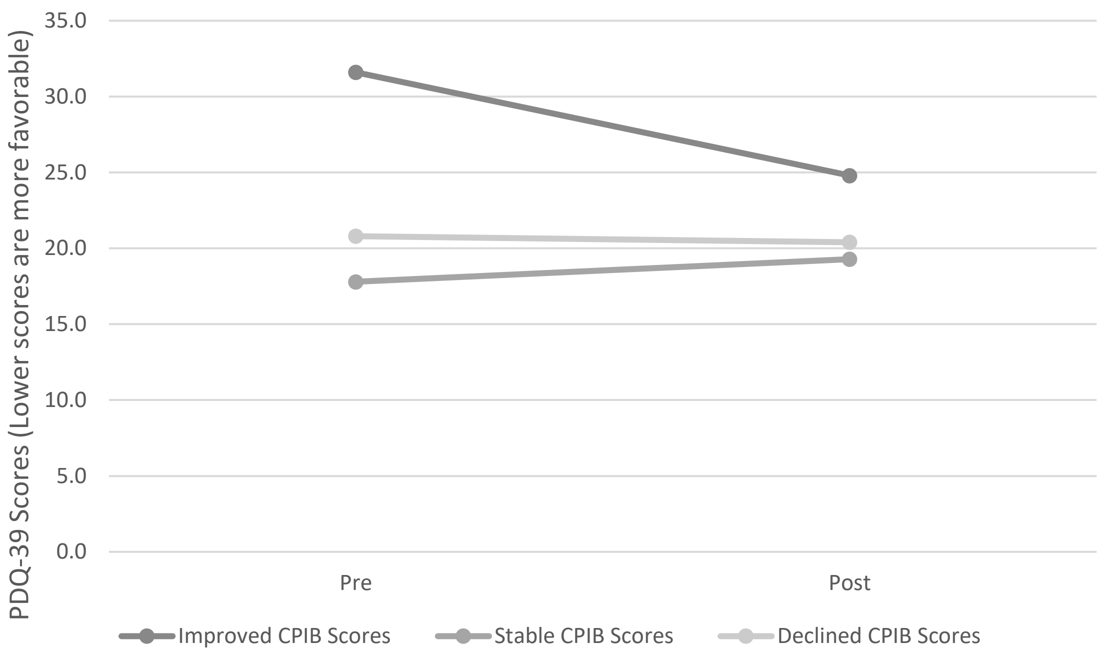
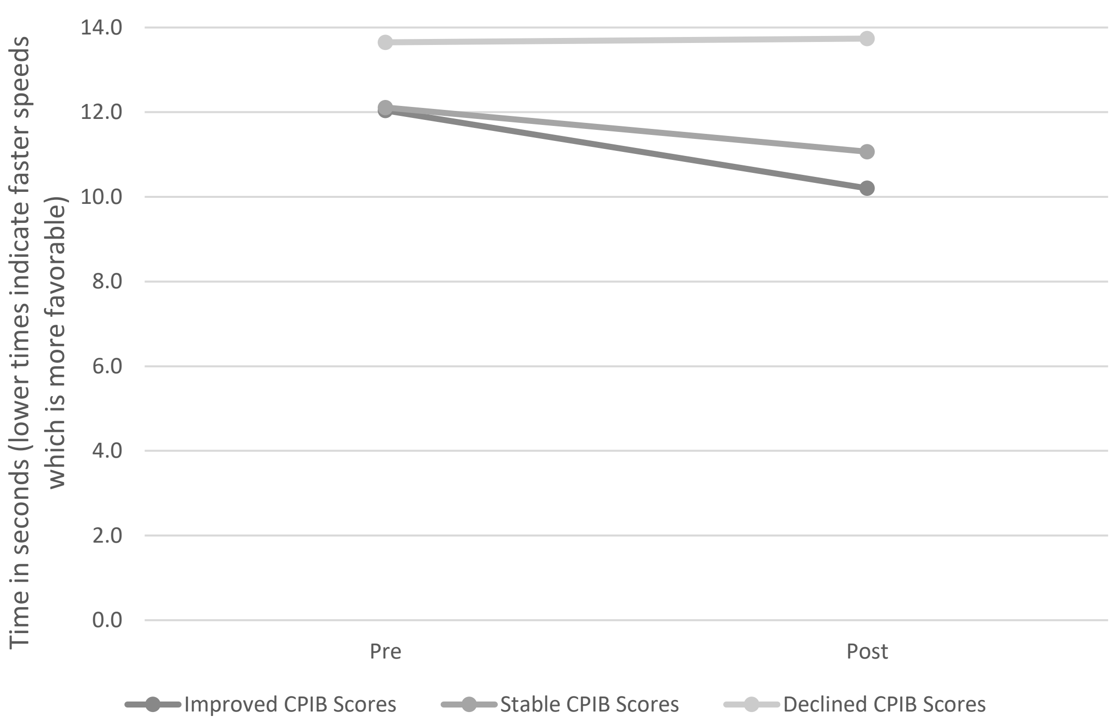


FIGURE 19. Comparison of Five Time Sit to Stand times pre to post within groups according to CPIB score's direction of change



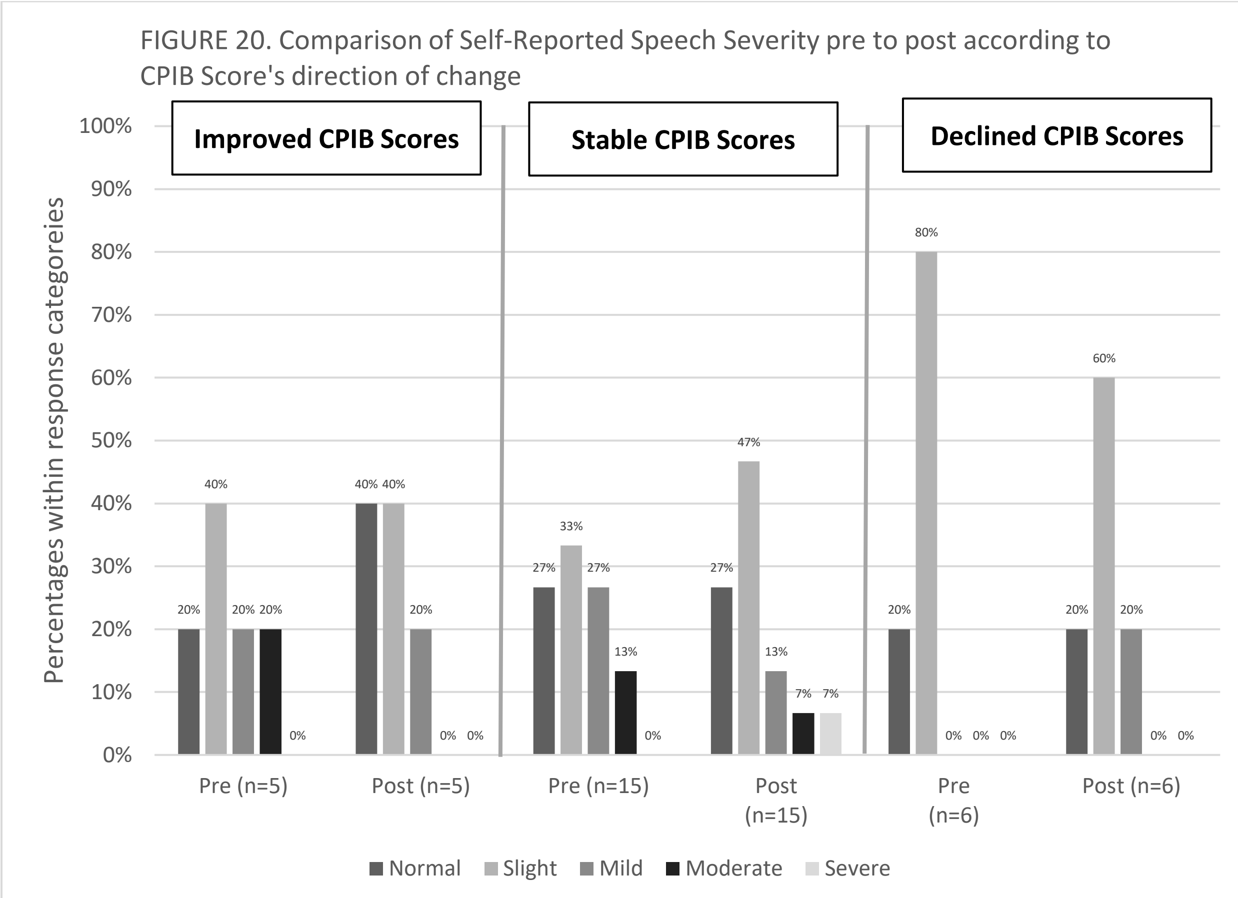


FIGURE 20. Comparison of Self-Reported Speech Severity pre to post according to CPIB Score's direction of change
Improved CPIB Scores
Stable CPIB Scores
Declined CPIB Scores
Percentages within response categoreies
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Pre (n=5)
Post (n=5)
Pre (n=15)
Post (n=15)
Pre (n=6)
Post (n=6)
Normal
Slight
Mild
Moderate
Severe

FIGURE 21. Comparison of Self-Report Chewing/Swallowing Difficulty pre to post accordng to CPIB Score's direction of change

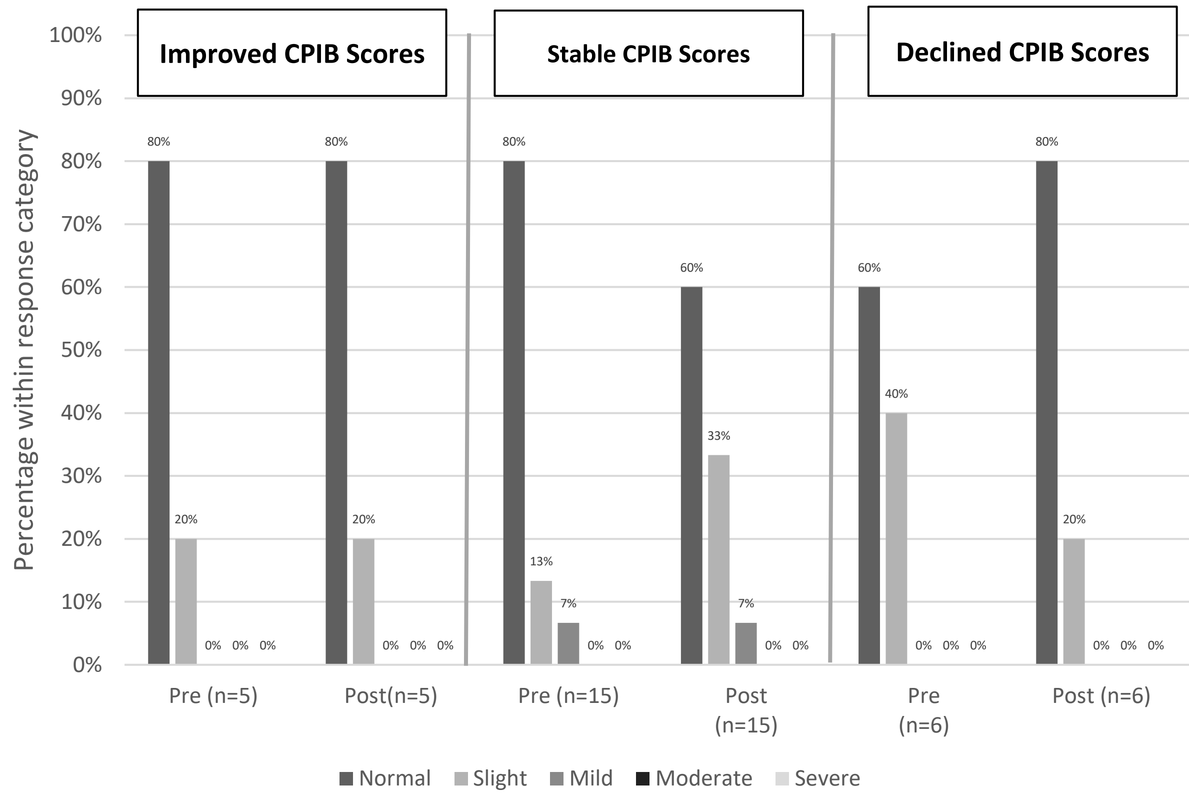
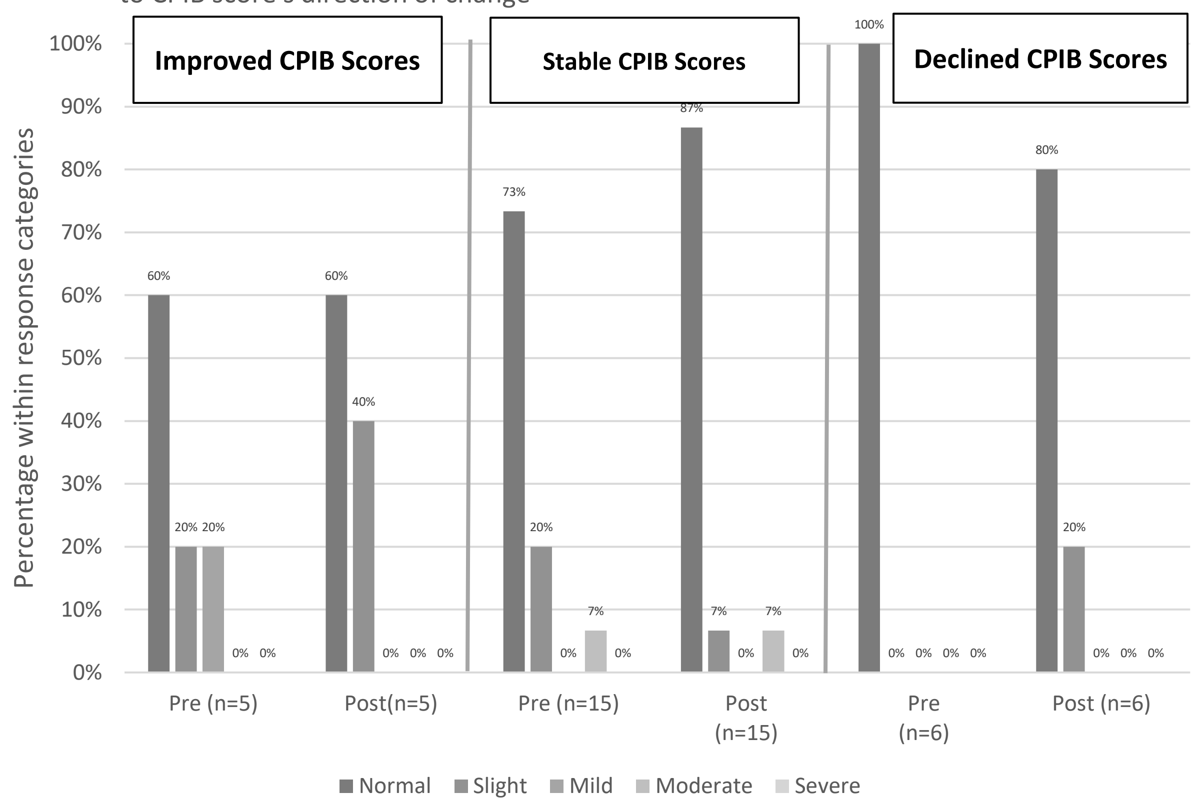



FIGURE 22. Comparison of Self-Reported Eating Difficulty pre to post according to CPIB score's direction of change
Improved CPIB Scores
Stable CPIB Scores
Declined CPIB Scores
Percentage within response categories
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Pre (n=5)
Post(n=5)
Pre (n=15)
Post (n=15)
Pre (n=6)
Post (n=6)
Normal
Slight
Mild
Moderate
Severe

FIGURE 23. Comparison of Self-Reported Tremor Difficulty pre to post according to CPIB score's direction of change



Question 4

"In a sub-group of participants for whom data are available, what is the association between CPIB scores and speech intelligibility as measured by the SIT for time point 1?"

With this final question, data from 15 of the original 41 participants were available for analysis based on participants for whom SIT sentences were recorded and scored. Demographic data for these 15 participants are available in Table 8. The majority of this sample were male (60%), with an average age of 62.3 years and an average time since diagnosis of PD of 5 years.

TABLE 8. Demographics of Participants for Question 4 (n=15)

		Results	
Demographic Variable		Mean (SD)	Range
Age		62.3 (7)	54-75
Years since Diagnosis		5 (5.3)	>1 - 14
Demographic Variable		Frequency	% (n=32)
Gender	Female	6	40
	Male	9	60

For this question, the association between the CPIB and the variables of speech intelligibility and self-reported speech severity were explored. Self-reported speech severity was also included in the correlations in Question 1 with the larger sample of participants (n=32), but this variable was re-examined for this question in order to include examination of its associations with speech intelligibility as well. Pearson product-moment correlation was used to examine the association between the CPIB and sentence intelligibility. Spearman correlations were used to examine the associations between CPIB and self-reported speech severity, and between speech intelligibility and self-reported speech severity. Analyses were conducted with SPSS 18.0. Mean, SD, and frequency of responses are shown in Table 9.

TABLE 9. Summary of descriptive results for CPIB, SIT, and Self-reported Speech Severity used in question 4 (n=15)

Measure	Description	Results		
		Mean (SD)		Range
CPIB	Measures self-reported interference with communicative participation; Scores reported in T-scores (mean=50-; standard deviation = 10). Higher scores are more favorable.	56.9 (10)		40.1 – 71
SIT	Rates speakers' intelligibility by recording participants speech as read from standardized sentences of specific lengths, transcribing sentences, and averaging percentage of words understood across listeners.	97.4% (1.7%)		92.7 – 99.7%
		Variable	Frequency	Percentage
Self-Reported Speech Severity	Self-report scale from the UPDRS that has participants rate the severity of their speech on a 5 point scale from "Normal" to "Severe."	Normal	2	13.3
		Slight	7	46.7
		Mild	5	33.3
		Moderate	1	6.7
		Severe	0	0

Note. CPIB = Communicative Participation Item Bank, UPDRS = Unified Parkinson Disease Rating Scale

Results suggest the correlation between the CPIB and the variable of speech intelligibility was weak at $r = -.021$. The negative correlation was somewhat unexpected as it technically implies that better communicative participation is associated with lower speech intelligibility. However, the weakness of the correlation implies that there is no strong association between the two variables, thus, the negative direction may not actually be meaningful. Close inspection of the data revealed several examples of this disparity between CPIB scores and speech intelligibility with one participant who scored low on the CPIB (T=41; or 1 SD below the mean) having highly intelligible speech (99%), and another participant scoring high on the CPIB (T=62; greater than 1 SD above the mean), but having lower intelligibility (92%) . Restriction of range might also account for the weakness of the correlation as the 92% intelligibility rating mentioned above was the lowest rating within this group of participants which demonstrates that most of the participants were highly intelligible.

Moderate correlations were observed between the CPIB and self-reported speech severity (-.432). This result is interpreted as better communicative participation being moderately associated with less severe speech symptom per self-report. This correlation was negative because lower scores on the speech severity self-report scale indicate less severe speech symptoms.

Finally, the correlation between speech intelligibility and self-reported speech severity was weak with $r = .017$. The direction of this correlation was also unexpected as it implies better speech intelligibility is associated with more severe self-report speech symptoms. Weakness of the correlation once again suggests that because these variables to not appear to be strongly associated, the direction of the correlation is not meaningful. None of the correlations examined for Question 4 were statistically significant at the $p<.05$ level.

Discussion

The purpose of this study was to examine the potential impact an intervention targeting physical function through a community-based cycling program would have on speech outcomes and communicative participation in Parkinson’s disease (PD). The primary focus of the analyses in this paper was exploration of the CPIB, an instrument designed to measure the construct of communicative participation which includes the effects of a communication disorder on a person’s ability to participate in the communication aspects of their lives. The data analyzed were part of a primary investigation that explored the feasibility of a tandem cycling exercise program using augmented aerobic exercise. This larger study explored many variables including the impact of a 10-weelk cycling program on physical function. Additional data collected in the primary study included cognitive function, QOL, and depression screening test. With the primary study's focus on motor function, and because speech is primarily a motor function that is often impacted with the progression of the disease, the research team decided to collect the speech outcome data which is the portion that is being investigated in the current study. The speech data served as a control measure as it was not expected to change. With the inclusion of the CPIB in the speech battery, this also provided researchers a first glimpse into the CPIB's stability over time within a group of participants.

The first purpose of this investigation was to examine the relationship of the CPIB to a selection of variables included in the larger study. In summary, the results suggested that better communicative participation was most strongly associated with less tremor, better quality of life, and less severe impact of PD symptoms on ADLs. Better communicative participation was also revealed to have moderate associations with shorter time since diagnosis of PD, and less severe speech, chewing/swallowing, and eating difficulties. Self-reported speech usage was not strongly associated with the CPIB. Physical function demonstrated very weak associations with the CPIB.

These particular findings compare to existing studies in that the CPIB appears to be consistently associated with self-reported speech severity (Baylor et al., 2010; Bolt et al., 2016; McAuliffe et al., 2016; Yorkston et al., 2014, submitted). The only difference in the current study is that the association between CPIB and self-reported speech severity was moderate as compared to the strong associations found in prior studies. The moderate association revealed here could be explained by the smaller sample size. McAuliffe et al. conducted the only other study known that has specifically investigated the CPIB in PD (2016). Both their results and the current findings suggest swallowing difficulties to be associated with lower CPIB scores.

Existing literature that differs from the current investigation suggested that in PD, better communicative participation was associated with factors such as lower speech usage, fatigue, cognitive problems, and emotional problems. None of the outcome measures used in this analysis addressed fatigue directly, thus no interpretation can be made about its association in this study, but could be investigated further in future research. Global cognitive and emotional problems were examined with the MOCA and GDS respectively in this study. However, neither of these instruments demonstrated significant correlations with the CPIB. One possible explanation might include how the MOCA and GDS were scored. Both provided only binary results (i.e., Mild Cognitive Impairment/No Mild Cognitive Impairment; Depressed/Not Depressed), so this may impact their sensitivity when used in a correlation analysis. Tools with finer-grained scoring for these constructs could be used in future research to assess if this would have any impact on results.

The second purpose of this study was to examine characteristics and trends within groups according to the level of CPIB scores (high, mid, low). Results suggested participants with low CPIB scores consisted of a higher percentage of males, had longer time since diagnosis of PD, lower QOL, and more participants endorsing difficulty with chewing/swallowing, ADLs, eating, and tremor. The high and mid groups – which included all participants who scored above the mean – had similar results to each other. Self-reported speech-severity levels were seen to be variable across all three groups, but reveal gradually increasing number of responses in more severely involved categories as CPIB scores moved from high to low. This suggests that, as might be expected, people who endorse less difficulty with speech might have better communicative participation and that those who endorse more difficulty with speech might have worse communicative participation.

Overall, the comparisons of these three subgroups suggest that in the future, researchers could potentially explore different factors and their associations at different levels along the CPIB scale in larger sample sizes. Finding the factors with the strongest level of influence on the CPIB could inform which factors to flag in early assessment in the progression of PD. This may be particularly relevant for PD and other progressive diseases because of the high likelihood of worsening symptoms.

The third purpose of this investigation was to examine changes in CPIB scores over time. Results from a paired *t*-test suggested no significant difference in CPIB scores pre to post. Examination of scores pre to post within the high, mid, and low groups supported this result as evidenced by lack of meaningful difference in group statistics pre to post, and wide variation in individual participant trajectories. Upon examination of participants based on whether their CPIB scores improved, declined, or stayed relatively stable, results suggested that participants whose CPIB scores improved also had improvements on several other variables including physical function, quality of life, and self-reported variables of speech severity, difficulties with ADLs, and tremor. The other two groups (declined and stable CPIB) did not appear to have specific trends in one direction or another in terms of changes in other variables examined. As this was the first attempt to examine changes in CPIB over time, no known studies were found to which these results could be compared. The stability of group-level scores over time provides preliminary evidence of test-retest reliability for the CPIB. However, although group level data remained stable, many participants scores did change over time which highlights the need for clinicians to be mindful and consider this on a client by client basis.

The final purpose of this study was to analyze the associations between CPIB scores, speech intelligibility, and self-reported speech severity. Results revealed weak correlations between CPIB scores and speech intelligibility, as well as between speech intelligibility and self-reported speech severity, but did reflect a moderate association between the CPIB and self-reported speech severity which was also reflected in the analysis completed on the larger sample. As mentioned above, most explorations on factors associated with the CPIB have revealed strong correlations with self-reported speech severity (Baylor et al., 2010; Bolt et al., 2016; McAuliffe et al., 2016; Yorkston et al., 2014, submitted). These results also corroborate existing research that suggested that minimal or no relationship existed between objective measurements of speech intelligibility and communicative effectiveness in those with PD (Dykstra, Adams, & Jog, 2015). Although addressing a different population, another study exploring communicative participation in patients with head and neck cancer showed similar results with low correlations between the CPIB and speech intelligibility (Eadie et al., 2016). All of these results further support the notion stated by McAuliffe et al. (2016) in their investigation of the CPIB and PD that an individual's perception of their speech may have greater influence on communicative participation than the results of objective measurement such as speech intelligibility.

The current study, in conjunction with existing research, informs clinical practice by adding to the ever-growing data that support the relationships between different variables (many of them not related to speech) and communicative participation. Additionally, understanding that communicative participation is a phenomenon that is based on an individual's subjective experience and that it is not always reflected in objective measures of speech mechanics should encourage speech pathologists to be mindful of associated factors and to be deliberate in their assessment of communicative participation (as opposed to making inferences about participation based on clinical severity measures). Furthermore, this study highlights not only the test-retest reliability of the CPIB as a tool for measuring communicative participation, but also highlights the individual changes that occur below the group level statistics, thus emphasizing the importance of clinicians being mindful of individual client experiences. Beyond the field of speech-language pathology, other allied health professionals could also benefit from understanding relationships between associated factors and communicative participation in order to more easily recognize when participation is being restricted, thus hastening the referral process that could make the difference in the life of a person with PD.

The primary limitations of this study were its small and variable sample sizes. This was due to the secondary data analysis of this investigation and feasibility issues of gathering speech data from all participants at all time points. Further limitations included restriction of range in some variables, particularly in sentence intelligibility. Larger sample sizes containing a broader range of values for each variable would provide a clearer understanding of the extent and nature of relationships among the variables. A final point to be noted is that results cannot be generalized to other disordered populations as this study examined solely people with PD.

This study gives some direction for further research to continue exploration of the CPIB and associated factors. Especially interesting were the differences seen in the different subgroups of the CPIB, specifically the high, mid, and low groups which revealed potentially meaningful differences in other variables for those with CPIB scores below the mean. This was particularly interesting because this pattern was revealed consistently within several variables and no similar patterns were noted in either of the other two groups. Further research into these differences along the CPIB scale may add depth to the CPIB’s utility as a measurement tool. Not only would it help clinicians better understand communicative participation, but by identifying potential traits that are common among people with CPIB scores at a certain level, speech pathologists could become better equipped at noting concomitant issues and be quicker to make appropriate referrals. Just as other researchers have suggested the need for speech pathology referrals earlier on in a person's progression of their PD symptoms (Miller, 2012), so could speech pathologists strive to promote interdisciplinary awareness and timely referrals for overall improvement in patient outcomes. Furthermore, although physical outcome measures did not show strong associations with the CPIB, researchers in rehabilitation medicine might continue to consider collaboration to explore the interactions between the different domains such as was attempted here with physical therapy and speech pathology. Additionally, similar in-depth investigations on the CPIB within other disordered populations could add to its strength and credibility as a useful clinical tool.

Conclusions

This study added to the ever-growing body of research that points to the complex nature of communicative participation. As the first study to look at CPIB scores across time, this study specifically highlighted the CPIBs stability. Further exploration into the characteristics of groups of people with low, mid, and high CPIB scores could also aid in finding optimal solutions for a person's recovery as well as further exploration into the characteristics of groups of people based on their scores' trajectories. This could inform which of factors might influence a person towards improving their communicative participation versus what factors might be causing people to decline.

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Appendix A

Breakdown of Samples sizes and outcomes measures used for each research question:

Question	Participants	Outcome Measures	Analyses
1. What are the correlations between CPIB scores and outcome measures of daily living, quality of life, depression, overall cognition, and physical function respectively at time point 1 (pre-intervention time point)?	N = 32	Pre-Treatment Data from: • CPIB • Speech Usage • SIT • UPDRS • PDQ-39 • GDS • MoCA • Gait Speed • TUG • FTSS	Pearson product-moment correlations AND Spearman Correlations (dependent on data-type; see methods)
2. Do sub-groups of participants based on severity of CPIB scores differ on demographic or other measures?	N = 32	Demographic Data: • Age • Gender • Time p/o • Variables with strong associations from Q1	Descriptive Analysis (data was be visually analyzed for sub-groups based on CPIB scores)
3. *A.* Did CPIB scores change for the group as a whole after individuals with PD participated in a tandem cycling exercise program?	N = 26	Pre-Post Data: • CPIB scores	Paired t-test
B. Are there trends and/or common characteristics among the sub-groups of participants identified in question #2 above in terms of whether or not their CPIB scores changed after the tandem cycling intervention?	N = 26	Pre-Post Data: • CPIB Scores – sub-groups as defined in question 2	Descriptive Analysis
C. Are there trends and/or common characteristics among sub-groups of participants who reported improved communicative participation, deteriorating communicative participation, or no change in communicative participation during the tandem cycling	N = 26	Pre-Post Data: • CPIB Scores – sub-groups based on direction of change over time.	Descriptive Analysis

program?			
4. In a sub-group of participants for whom data are available, what is the association between CPIB scores and speech intelligibility as measured by the SIT for time point 1?	N = 15 (total to be determined depending on quality of recordings)	Pre-Treatment Data: • CPIB scores • SIT intelligibility • SR Speech Severity	Pearson Product-Moment Correlation & Spearman Correlations

Appendix B

Question 2 of the current study examines 26 participants based on CPIB scores at the first time-point. However, the figure does not appear representative of 26 scores. This is explained by some significant overlap that is visually represented below. Any score that is grayed out will not appear in the figure because that number already occurred.

Overlapping CPIB Scores for Figure 1 in Question 2				
High:		Mid:		Low:
71		54.00		44.4
66.7		57.8		32.4
64.2		60.6		42.2
66.70		60.60		41.1
71.00		60.6		49
64.2		56.5		47.8
66.7		52.7		40.1
71		57.8		41.1
71		57.8		40.1
64.2		59.2		
		56.5		
		51.50		
		52.7		