

Determining the Applicability of the Cognitive Orientation to daily Occupational Performance (CO-OP) as a Meta-Cognitive Rehabilitation Strategy for Individuals with Cognitive Impairment in Parkinson's Disease

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ABSTRACT

Background: Cognitive impairment is a non-motor symptom of Parkinson's disease (PD) experienced by over 50% of people with PD. Cognitive rehabilitation has been acknowledged as a beneficial treatment for people with PD, but little research has been published on its effectiveness on occupational performance or health-related quality of life. While not yet studied in people with PD, the Cognitive Orientation to Occupational Performance (CO-OP) has potential to be an effective treatment tool.

Purpose: The objectives of this study were to understand the effects of the CO-OP on successful engagement in desired occupations, participant-perceived health-related quality of life, and caregiver stress / burden, and to examine the usefulness of the CO-OP as a clinical treatment approach for individuals with PD.

Methods: A concurrent mixed methods procedure with an interrupted time series A-B-A single-subject design was used. Three participants with PD and their spouses were recruited from a movement disorder clinic at an urban geriatric care centre. Data were collected using the Canadian Occupational Performance Measure, the Parkinson Disease Questionnaire-39, the Zarit Burden Interview, semi-structured interviews, and direct observation. Quantitative data were analyzed using statistical and visual analysis, while qualitative data were analyzed using interpretive description. Analyzed quantitative and qualitative data were combined to gain a comprehensive understanding of the study results.

Results: By the end of CO-OP treatment, all three participants with PD were able to successfully engage in desired occupations that they had self-selected for their treatment goals. Successful

engagement took place for all three trained goals as well as both untrained goals for each participant. Findings showed that participants were able to generalize the CO-OP strategies to perform trained goals on their own outside of treatment and transfer the CO-OP strategies they had learned to perform untrained goals. Continued use of the CO-OP strategies was sustained by only one participant three months following treatment; findings of the benefits of the CO-OP program were sustained for that participant but not for the two participants who were no longer using the CO-OP strategies. Participants and caregivers found the treatment program beneficial to improve awareness of the participants' cognitive difficulties for both the participants themselves and the caregivers. The CO-OP program did not appear to affect health-related quality of life for participants nor did it affect caregiver stress / burden.

Conclusions: Individuals with PD-related cognitive impairment are capable of successfully engaging in self-selected treatment goals that are trained during CO-OP treatment sessions, generalizing the CO-OP strategies they have learned in treatment in order to successfully engage in the same goals outside of treatment, and transferring their new knowledge of the CO-OP strategies in order to successfully engage in untrained goals independently. Treatment effects can be difficult to maintain beyond the end of formal treatment sessions. The CO-OP protocol is helpful to increase awareness of cognitive difficulties for individuals with PD-related cognitive impairment and to increase caregiver awareness of these cognitive difficulties. Increased awareness of cognitive difficulties is helpful for individuals with PD-related cognitive impairment to learn to restructure their thinking in order to achieve goals related to day-to-day activities. Increased caregiver awareness of cognitive difficulties in their loved ones can help to improve caregivers' coping skills and empathy for their loved ones.

Practice Implications: Findings from this study are promising and provide support for conducting further study with longer pre-intervention phases and larger sample sizes to better determine the usefulness of the CO-OP as a clinical treatment approach for individuals with Parkinson's-related cognitive impairment and their caregivers.

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DEFINITIONS

Babcock Story Recall Test: A measure of verbal memory. Scores on the Babcock's Story Recall Test are strongly correlated with scores on the Wechsler Memory Scale-Revised Logical Memory scores (Horner, Teichner, Kortte, & Harvey, 2002).

Basic activities of daily living: Basic personal care tasks that an individual engages in on a daily basis, such as eating, dressing, bathing, toileting, and grooming (Mosby, 2012).

Celeration line: "a best fit line through the data beginning in the first phase and extending through each phase in the study," used in visual interpretation of data changes between study phases (Fetters & Tilson, 2012, p. 118).

Client-centred practice: An approach to health care service delivery that "places the client at the centre of the clinical decision-making process," (Stern, Restall, & Ripat, 2000, p. 145).

Cognitive rehabilitation: A systematic, functionally oriented treatment approach using cognitively therapeutic activities designed to decrease cognitive functional impairment and improve participation in meaningful occupations for individuals with cognitive impairment

(Calleo et al., 2010; Pyung et al., 2009). The term “cognitive rehabilitation” is often used interchangeably in the literature with “cognitive training,” “cognitive remediation,” and “cognitive compensation” (Calleo et al., 2012; Mohlman, Chazin & Georgescu, 2011); Nombela et al., 2011; Paris et al., 2011; Sammer et al., 2006; Sinforiani et al., 2004). Components of cognitive rehabilitation generally include rehabilitative skills training and teaching of compensatory techniques related to basic and instrumental activities of daily living; however, all studies found in the literature review for this thesis examined the effects of rehabilitative skills training only; no available study assessed the effects of cognitive compensation strategies. Specific cognitive domains targeted for rehabilitation in the literature include attention (sustained, selective, alternating, and divided), working memory, memory, psychomotor processing speed, executive functions (abstract reasoning, task switching, rule shifting), and visuospatial skills (Goebel, Mehdorn, & Leplow, 2010; Mohlman, Chazin, & Georgescu, 2011; Nombela et al., 2011; Paris et al., 2011; Sammer et al., 2006; Sinforiani et al., 2004).

Cognitive status: The state of an individual’s mental functions including memory, attention, language, perception, and problem-solving (Harper Collins, 2006).

Executive functions: The cognitive processes involved in deliberate planning, performing, and regulating complex, goal-directed behavior. These processes involve the inhibition of automated responses, retrieval of information from declarative memory, planning, sequencing, set-shifting,

maintenance and retrieval of information from working memory, and self-monitoring (Foster & Hershey, 2011; Koerts, van Beilen, Tucha, & Brouwer, 2011).

Health-related quality of life: The aspects of quality of life that are known to affect either physical or mental health. These aspects include an individual's health conditions, risks to health, functional status, socioeconomic status, and social supports, as well as community resources, conditions, policies, and practices that may affect the health perceptions and functional status of an entire population (Centers for Disease Control and Prevention, 2013).

Instrumental activities of daily living: Meaningful activities that are usually performed by an individual living independently in the community that are part of their typical day, such as managing finances, making telephone calls, grocery shopping, preparing meals, community transportation, and housecleaning (Mosby, 2012).

Interpretive description: "An inductive analytic approach designed to create ways of understanding clinical phenomena that yield applications implications," (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004, p. 1).

Interrupted time series design: A study design with multiple discrete phases over time. In its simplest form, this design begins with a baseline phase during which repeated measures are

taken of a dependent variable to establish a baseline pre-intervention pattern. Repeated measures are taken again during the intervention phase, then again after the intervention has been withdrawn. The mean of the data gathered during the intervention phase is compared to the means of the pre- and post-intervention phases to determine if the intervention has had any effect on the baseline pattern.

Meta-cognitive: having to do with “knowledge about one’s own cognitive processes” (Wiley, 2005).

Mild cognitive impairment: “An intermediate level of cognitive function between ‘normal’ and ‘demented’” (Calleo, Burrows, Levin, Marsh, Lai, & York, 2012, p. 2). Scores on the Montreal Cognitive Assessment (MoCA) falling above 16 and below 26 out of a total score of 30 are indicative of mild cognitive impairment (Hoops, et al., 2009). A Movement Disorder Society commissioned task force has defined mild cognitive impairment in Parkinson’s disease (PD-MCI) as a syndrome defined by inclusion of all of the following criteria: 1) a diagnosis of Parkinson’s disease; 2) gradual cognitive decline, reported by either the individual himself or herself, an informant, or observed by a clinician, that has begun after a diagnosis of Parkinson’s disease has been established; 3) cognitive impairment as measured on a scale of global cognitive abilities (such as the Montreal Cognitive Assessment) or formal neurological testing; 4) cognitive impairment that is not severe enough to significantly alter the individual’s functional

independence, although mild difficulties may exist with complex functional tasks (Litvan, et al., 2012).

Occupation: “Everything people do to occupy themselves, including all activities and tasks of everyday life including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their community (productivity)” (Canadian Association of Occupational Therapists, 1997, p.3).

Occupational performance: “The ability to choose, organize, and satisfactorily perform meaningful occupations” (Fearing & Clark, 2000, p. 56).

Occupational performance issue: Anything that prevents a congruent fit between a person, his or her environment, and his or her occupation (Canadian Association of Occupational Therapists, 1997).

Parkinson’s Disease Dementia: Typically involves severe global cognitive impairment in at least two areas: attention, memory, language, visuospatial functions, and executive functions that significantly interfere with occupational performance and quality of life (Emre, Aarsland, & Brown, 2007; Moberg, 2007).

Raven's Matrices: a widely used measure of executive functions including working memory, nonverbal reasoning, visuospatial perception, and problem solving (Rao & Baddeley, 2013; (Tomic, Vladetic, Solic, Misevic, & Soldo, 2013).

Single-Subject Design: A research design intended to follow one participant intensely. During a baseline period, the variables of interest are repeatedly measured (can be over days or weeks) in order to establish typical patterns of variability for the participant. After the baseline pattern has been established, the intervention phase begins, during which data on the participant is measured periodically. There may also be a second baseline phase (withdrawal phase) after the intervention has been completed, during which the participant is measured but no treatment is given (Fetters & Tilson, 2012).

Two-standard deviation band: A statistical analysis method often used in combination with a celeration line in single subject design to visually interpret data changes between study phases (Fetters & Tilson, 2012).

Visual analysis: “reaching a judgment about the reliability or consistency of intervention effects by visually examining the data,” (Kazdin, 2011, p. 232).

WHO-DAS II: World Health Organization Disability Assessment Schedule II: a measure of functional disability based on the International Classification of Functioning, Disability, and Health (World Health Organization, 2011).

Young-onset idiopathic Parkinson's disease: Onset of idiopathic Parkinson's disease before age 40 (Parkinson Society Canada, 2013).

1.0 INTRODUCTION

1.1 Statement of the problem

Parkinson's disease (PD) is a progressive neurodegenerative disorder affecting approximately 100,000 Canadians and approximately 1% of the global population over age 60 (Nussbaum & Ellis, 2003; Parkinson Society Canada, 2003). Between the years 2005 and 2030, it is expected that the prevalence of Parkinson's disease will more than double in the world's most highly populated countries (Dorsey, et al., 2007). Parkinson's disease is characterized by its cardinal motor features of tremor, rigidity, bradykinesia, and postural instability (Emre, Aarsland, & Brown, 2007; Parkinson's Society Canada, 2012). The non-motor symptoms of Parkinson's disease, such as cognitive impairment, neuropsychiatric symptoms, autonomic symptoms, sensory impairment, sleep disturbances, and fatigue are gaining more clinical and research attention (Park & Stacy, 2009; Postuma & Galatas, 2012).

Cognitive impairment is a non-motor symptom of Parkinson's disease that is experienced to varying degrees by over 50% of cases (Moberg, 2007), with higher risk with increasing age and severity of motor impairment (Emre, Aarsland, & Brown, 2007). Cognitive impairment in Parkinson's disease has a distinct pattern, with typical impairments experienced in attention (sustained, selective, alternating, and divided), information processing speed, memory recall, visuospatial skills, psychomotor functions, and executive functions (Botha & Carr, 2012; Emre, Aarsland, & Brown, 2007; Mohlman, Chazin, & Georgescu, 2011; Park & Stacy, 2009; York & Alvarez, 2008). Even for individuals with mild cognitive impairment, impairments in these cognitive areas are known to negatively affect quality of life for people with Parkinson's disease

and their caregivers (McKinlay, Grace, Dalrymple-Alford, & Roger, 2010; Paris, et al., 2011; Sammer, Reuter, Hullmann, Kaps, & Vaitl, 2006; Sinforiani, Banchieri, Zucchella, Pacchetti, & Sandrini, 2004). Cognitive deterioration in Parkinson's disease correlates with increased caregiver stress (McKinlay, Grace, Dalrymple-Alford, Anderson, Fink, & Roger, 2008) and earlier placement in long-term care (Aarsland, Larsen, Tandberg, & Laake, 2000; McKinlay, Grace, Dalrymple-Alford, & Roger, 2010). Importantly, researchers have reported that cognitive and behavioural impairments are often more disabling than the motor symptoms of Parkinson's disease (Global Parkinson's Disease Survey Steering Committee, 2002; Sammer, Reuter, Hullmann, Kaps, & Vaitl, 2006). Impairments in executive functions in particular can limit participation in desired occupations such as socialization, instrumental activities of daily living, productive work, and leisure activities, even if motor symptoms are well-controlled by medications (Foster & Hershey, 2011), and thus can also impact negatively on patient-perceived health-related quality of life (Eriksson, Kottorp, Borg, & Tham, 2009).

Since cognitive impairment in Parkinson's disease has a profound effect on health-related quality of life, there is a corresponding need to provide effective interventions to counteract the cognitive symptoms of the disease course and reduce functional impairment (Calleo, Burrows, Levin, Marsh, Lai, & York, 2012). Because of the incomplete efficacy of medications for cognitive symptoms in Parkinson's disease (Vale, 2008), and because many people with Parkinson's disease would prefer to minimize their use of medications (Leroi, Collins, & Marsh, 2006), alternative treatment modalities such as cognitive rehabilitation are appealing options to reduce impairment in occupational performance and improve quality of life for people with Parkinson's disease and their caregivers (Calleo, Burrows, Levin, Marsh, Lai, & York, 2012).

1.2 Significance of the study

Since 2004, cognitive rehabilitation has been increasingly acknowledged in the literature as a beneficial non-pharmalogical treatment for cognitive impairment in Parkinson's disease (Calleo, Burrows, Levin, Marsh, Lai, & York, 2012; Leung, Walton, Hallock, Lewis, Valezuela, & Lampit, 2015; Orgeta, McDonald, Poliakoff, Hindle, Clare, & Leroi, 2015; Ventura, Edwards, & Barnes, 2015). Although early results are promising, to date, little research has yet been published on the effects of cognitive rehabilitation in Parkinson's disease. Of fourteen unique studies published on the effects of cognitive rehabilitation in Parkinson's disease, only two (Paris, et al., 2011; & Peña, et al., 2014) have attempted to objectively measure the relationship between improved cognition from a cognitive therapy program and function in everyday occupations. Several studies in the literature demonstrate the association between cognitive status and occupational performance in Parkinson's disease and point to the need for individualized cognitive treatment programs, in realistic environments, to encourage translation of training to improve occupational performance in both basic and instumental activities of daily living (Disbrow, Russo, Higginson, Yund, Ventura, & Zhang, 2012; Foster & Hershey, 2011; Koerts, van Beilen, Tucha, & Brouwer, 2011; Pyun, Yang, Lee, & Yook, 2009; Rosenthal, et al., 2010).

The Cognitive Orientation to daily Occupational Performance (CO-OP) is a global, client-centred rehabilitation approach in which the client is guided to use a meta-cognitive problem-solving strategy to perform self-identified goals using guided discovery (Dawson, Gaya, Hunt, Levine, Lemsky, & Polatajko, 2009; Polatajko & Mandich, 2004). First developed for use in children, emerging evidence in the adult population shows promising results for the effect of

the CO-OP for individuals with impairment in executive functions following traumatic brain injury and stroke (Dawson, Gaya, Hunt, Levine, Lemsky, & Polatajko, 2009; Dawson, Binns, Hunt, Lemsky, & Polatajko, 2013; Ng, Polatajko, Marziali, Hunt, & Dawson, 2013; Poulin, Korner-Bitensky, Bherer, Lussier, & Dawson, 2016; Skidmore, Holm, Whyte, Dew, Dawson, & Becker, 2011). Not examined in the Parkinson's population prior to this study, the CO-OP has the potential to be an effective treatment tool to improve performance in daily occupations for individuals with Parkinson's-related cognitive impairment.

2.0 REVIEW OF THE LITERATURE

2.1 Summary of the Literature on Cognitive Rehabilitation in Parkinson's Disease

A systematic review of the Cochrane database, PubMed, CINAHL, Scopus, OTSeeker, OTDatabase, PsychINFO, and PsychBITE was completed between May 14 and 17, 2012 using the following search terms: (1) “cognitive rehabilitation” OR “cognitive compensation” OR “cognitive training” OR “cognitive remediation”; AND (2) “cognitive impairment” OR “dementia” OR “mild cognitive impairment” OR “executive function” OR “executive dysfunction”; AND (3) “Parkinson's disease” OR “Parkinson” OR “parkinsonism” OR “parkinsonian disorders” OR “idiopathic Parkinson's disease.” Articles were included if they were original research, published in the English language, described a cognitive rehabilitation intervention intended to have an effect on cognitive function, and included individuals with Parkinson's disease. Articles were not included if they described a motor training intervention used either alone or in combination with another intervention intended to have an effect on cognitive function. The systematic search yielded a total of 594 unique articles. Of the titles and abstracts reviewed, 588 were excluded for not reporting original research (e.g., systematic and narrative reviews, $n = 59$), not being in English ($n = 32$), not reporting non-pharmacological cognitive rehabilitation interventions intended specifically to treat cognitive impairment (e.g. exercise interventions, interventions for gait, pharmacological interventions, $n = 354$), and subject population not including individuals with Parkinson's disease (e.g., individuals with Alzheimer's disease, individuals with Lewy Body dementia, $n = 143$). Six articles describing either cognitive rehabilitation, cognitive training, or cognitive remediation programs for people with Parkinson's disease were located. Of the six relevant articles found, one was a single-case study (Mohlman, et al., 2010), two were convenience sample studies with no control groups

(Mohlman et al., 2011; Sinfioriani et al., 2004), one was a convenience sample study with a control group (Nombela, et al., 2011) and two were small randomized controlled trials (Paris et al., 2011; Sammer et al., 2006). Periodic reviews of the Cochrane database, PubMed, CINAHL, Scopus, OTSeeker, OTDbase, PsychINFO, and PsychBITE between May 2012 and May 2016 as well as a systematic search of RehabData in May 2016 yielded nine additional relevant articles: one article on a convenience sample study without a control group (Naismith, et al., 2013), seven articles on randomized controlled trials (Angelucci, et al., 2015; Cerasa, et al., 2014; Costa, et al., 2014; Edwards, et al., 2013; Petrelli, et al., 2014; Peña et al., 2014; and Zimmerman, et al., 2014), and an article describing one year follow-up results of a previously published randomized controlled trial (Petrelli, et al., 2015).

The following table summarizes all fifteen relevant articles found:

Table 2.1 Summary of Literature Review on Cognitive Rehabilitation in PD

Authors	Year	Study Design	N	Intervention	Intervention Frequency	Outcome Measures	Results
Mohlman et al.	2010	Case Study	1	Combined Cognitive Behavioural Therapy and cognitive enhancement intervention	Ten weekly 90-120-minute sessions	Structured clinical interview for DSM-IV, Hamilton Scales for Anxiety, Hamilton Scales for Depression, tests of executive functions (Digits Backward, Trails B, Digit Symbol)	Reduction in anxiety and depression symptoms, unchanged cognitive skills; subjective report of gains maintained at one and three months post-intervention
Sinforiani et al.	2004	Convenience sample with no control group	20	Computer software program for neuro-psychological training	Twelve 60-minute sessions twice weekly for six weeks	Tests of executive functions (Babcock Story Recall Test, FAS (phonological word fluency), Raven's matrices, Corsi-test, WCST, Stroop)	Improvement in verbal fluency, immediate and delayed memory for problem solving, and visuospatial reasoning; gains maintained at six months post-intervention
Mohlman et al.	2011	Convenience sample with no control group	16	Attention process training	Four 90-minute sessions for four weeks	Tests of executive functions (Digits Backward, Stroop, Trails B, FAS, COWAT)	Improvement on four tests of executive functions (Digits Backward, Stroop, Trails B, and FAS); no long-term follow-up
Nombela et al.	2011	Non-randomized controlled study	20	Cognitive training based on Sudoku exercises (<i>N = 5 participants with PD</i>) No training (<i>N = 5 controls with PD and 10 healthy controls</i>)	Daily sessions of one Sudoku table (4x4 grid with 2x2 blocks) for six months	Modified Stroop, fMRI scans	Improved reaction times, increased correct answers, decreased missing answers on Stroop; reduced cortical over-activation patterns, and increased complexity of patterns on fMRI after training in experimental group; no change in control group; no long-term follow-up
Naismith et al.	2013	Non-randomized controlled study	50	Psycho-education group and computer-based cognitive training programs (<i>N = 35</i>) Waitlist controls (<i>N = 15</i>)	Two hours per week for seven weeks	Tests of learning and memory retention (WMS-III: LOGMEM-I and LOGMEM-II), psychomotor speed (Trails A) mental flexibility (Trails B), and verbal fluency (COWAT)	Improvements in learning, memory retention, and knowledge related to healthy brain aging; no effects on psychomotor speed, mental flexibility, or verbal fluency; no long-term follow-up

Authors	Year	Study Design	N	Intervention	Intervention Frequency	Outcome Measures	Results
Sammer et al.	2006	Randomized Controlled Trial	26	Working memory tasks requiring executive functions (N = 12) Standard OT, PT and "physical treatment" (N = 14)	Ten 30-minute sessions over three-to-four weeks	Behavioral Assessment of the Dysexecutive Syndrome (BADS) subtests of executive functions	Improvement in experimental group on tasks associated with core executive functions; no improvement in control group; no long-term follow-up
Paris et al.	2011	Randomized Controlled trial	28	Individualized computerized training program (SmartBrain Tool) and paper-and-pencil exercises (N = 16) Speech therapy group (N = 12)	Three 45-minute sessions per week for four weeks	Tests of executive functions (Digits Forward, Stroop, semantic fluency, Trails B, Tower of London, Rey figure, RBANS-Line Orientation); GDS-15; Cognitive Difficulties Scale; PDQ-39	More improvement in experimental group than in control group on tests of executive functions; no change in mood, cognitive difficulty in ADL, or quality of life; no long-term follow-up
Edwards et al.	2013	Randomized Controlled Trial	87	Self-administered cognitive speed of processing training (SOPT) via computer program ("InSight") (N=44) No-contact control group (N=43)	20 hours of training in total – encouraged to work on program for 60 minutes 3 times weekly	Useful Field of View (UFOV)	Improved UFOV performance in both groups, but significantly greater improvement in experimental group; no long-term follow-up
Cerasa et al.	2014	Double blind randomized controlled trial	15	Computerized training of attention ability and information processing tasks ("RehaCom") (N=8) Computerized training of visomotor coordination (N=7)	Twelve 60-minute sessions over six weeks	Tests of executive functions (Rey figure, Selective Reminding Test, Digits Forward, Judgment Line Orientation Test, SDMT, PASAT, COWAT, Trails A & B); fMRI scans	Improvements in performance scores on SDMT and Digits Forward in experimental group compared to control group; increased intrinsic functional activity in left dorsolateral prefrontal cortex in left central executive resting state network on fMRI in experimental group compared to control group; no long-term follow-up

Authors	Year	Study Design	N	Intervention	Intervention Frequency	Outcome Measures	Results
Costa et al.	2014	Double blind randomized controlled trial	25	Set-shifting training using pencil-and-paper exercises (<i>N=9 individuals with PD</i>) Language and respiratory exercises (<i>N=8 individuals with PD</i>) Control group without PD (<i>N=8</i>)	Twelve 45-minute sessions over four weeks	Tests of executive functions (PM procedure, verbal fluency test, Trails A & B)	Performance accuracy on PM procedure improved in experimental group but not in placebo group; no difference in PM procedure response times between experimental group and placebo group; performance on some components of verbal fluency test and on Trails B improved in experimental group; no change in verbal fluency test scores or Trails A or B in placebo group; no long-term follow-up
Peña et al.	2014	Single blind randomized controlled trial	42	Pencil-and-paper cognitive training (REHACOP) (<i>N = 20</i>) "Occupational activities" control group (<i>N = 22</i>)	Three 60-minute sessions per week for 13 weeks	Tests of executive functions, processing speed, verbal memory, visual memory, and theory of mind (Happé test); secondary outcomes were measures of neuropsychiatric symptoms (GDS, NPI-Q, Lille Apathy Rating Scale) and functional disability (WHO-DAS II, short version)	Improvement in processing speed, visual memory, theory of mind, and functional disability in treatment group versus control group; no improvement in executive functions in treatment group versus control group; no long-term follow-up
Petrelli et al.	2014 & 2015	Randomized controlled trial	65	Structured cognitive multi-component training – "NEUROvitalis" (<i>N = 22</i>) Unstructured, randomly assembled cognitive tasks – "Mentally fit" (<i>N = 22</i>) No treatment (<i>N = 21</i>)	Twelve 90-minute sessions over six weeks	Tests of executive functions (working memory - DemTect: digit span reverse; verbal fluency - DemTect: semantic and phonemic), attention (Brief test of Attention), memory, (DemTect, Memo, Complex figure) visuo-construction (Complex figure), depression, and quality of life (PDQ-39)	Improved working memory and short-term memory in NEUROvitalis group; improved depression scores in "Mentally Fit" group; no change in cognition test scores or depression scores in control group; no change in quality of life for any group Overall cognitive functions were maintained and risk for developing mild cognitive impairment was reduced in both treatment groups compared to control group at one year follow-up

Authors	Year	Study Design	N	Intervention	Intervention Frequency	Outcome Measures	Results
Zimmermann et al.	2014	Single blind randomized controlled trial	39	Computerized cognitive training program (CogniPlus) (<i>N</i> = 19) Motion-controlled computer sports game (Nintendo Wii) (<i>N</i> = 20)	Three 40-minute sessions per week for four weeks	Tests of executive functions, attention, working memory, visuo-construction, and episodic memory	Improved attention in group who played Nintendo Wii versus treatment group who completed CogniPlus training; no change in other measures; no long-term follow-up
Angelucci et al.	2015	Double blind randomized controlled trial	15	Paper and pencil set shifting exercises with gradually increasing difficulty (<i>N</i> = 7) Sustained attention and language exercises without variance of difficulty, respiratory exercises (<i>N</i> = 8)	Three 45-minute sessions per week for four weeks	BADS subtest of executive function, specifically planning (Zoo Map Test); Blood serum samples of Brain-derived neurotrophic factor (BDNF)	Improved planning skills and increase in BDNF blood serum levels in treatment group; no change in placebo group; no long-term follow-up

No information on the effects of cognitive rehabilitation in Parkinson's disease was published prior to 2004. From 2004 until the current date in 2016, a total of fourteen studies on the effects of cognitive rehabilitation in Parkinson's are known to have been published. All studies published prior to 2013 utilized small sample sizes of fewer than 30 participants, while several of the more recent studies have utilized larger sample sizes of up to 87 participants. The 2010 publication by Mohlman, et al., was a single case study that was limited by its lack of a control and the fact that the individual being studied had above-average intelligence prior to beginning the study, leading to a probable ceiling effect on treatment effects. Sinforiani, et al. (2004) and Mohlman, et al., (2011) used larger sample sizes than Mohlman et al.'s 2010 study,

but both these studies (Mohlman, et al., 2011; Sinforiani, et al. 2004) used convenience samples without control groups. Naismith, et al. (2013), and Nombela, et al., (2011), both improved upon previous study designs and used control groups, but both also used convenience samples. Nine randomized controlled trials have been published on the effects of cognitive rehabilitation in Parkinson's disease, the eight most recent of which have been published in 2013 or later. The first randomized controlled study was published by Sammer, et al., in 2006, while the second was published by Paris, et al., in 2011; both studies recruited under 30 participants. In 2013, Edwards et al. completed the largest randomized controlled study to date on cognitive rehabilitation in Parkinson's disease, with 87 participants. Five randomized controlled studies were published in 2014, with varying sample sizes ranging from 15 to 65 participants, most of which examined the effects of computerized training programs in comparison to other treatments (Cerasa et al., 2014; Petrelli et al., 2014; and Zimmermann et al., 2014), but two of which examined the effects of a pencil-and-paper training program in comparison to other treatments and to a control group with no treatment (Costa et al., 2014; Peña et al., 2014). In 2015, Angelucci et al. published the first known study of the effects of a paper-and-pencil set shifting training program on blood serum brain derived neurotrophic factor (BDNF) in comparison to a placebo group in a double blind randomized controlled trial. In their study, Angelucci et al. also examined the effects of their set shifting training program on executive functions in their treatment group in comparison to their placebo group. Among all published studies on cognitive rehabilitation in Parkinson's disease, treatment session length varied from 30 to 120 minutes, treatment frequency varied from daily to weekly, and treatment duration varied from three weeks to six months. Most publications found that cognitive rehabilitation in Parkinson's disease resulted in improvement in many cognitive functions, with the exception of the single case study

by Mohlman et al. (2010) and the randomized controlled trial by Zimmermann et al. (2014). Of the studies that showed improvement in cognitive functions, only Sinforiani et al. (2014) and Petrelli et al. (2014; 2015) completed long-term follow-up analyses, and both groups of authors found that improvements made during treatment were maintained over time. Only Paris et al. (2011) and Petrelli et al. (2014) examined the effects of cognitive rehabilitation on health-related quality of life, and only Paris et al. (2011) and Peña et al. (2014) examined the effects of cognitive rehabilitation on occupational performance in activities of daily living. Unfortunately, neither Paris et al. (2011) nor Petrelli et al. (2014) were able to find an effect of cognitive rehabilitation on health-related quality of life. Paris et al. (2011) did not find a treatment effect on occupational performance in activities of daily living for individuals with Parkinson's disease, but Peña et al. (2014) found that their cognitive treatment intervention improved occupational performance in activities of daily living for participants in their study's experimental group. None of the published studies have examined the effects of cognitive rehabilitation in Parkinson's disease on caregiver stress. The findings of this literature review indicate that, although study results thus far are promising, there is a need for further study of the effects of cognitive rehabilitation in Parkinson's disease, with further examination of the effects of cognitive rehabilitation on health-related quality of life, occupational performance, and a first look at the effects of cognitive rehabilitation on caregiver stress. Continuation of the more recent trend toward use of participant controls for comparison to treatment effects is also necessary, as is the use of larger sample sizes.

2.1.1 A Case Study

2.1.1.1 Mohlman et al., 2010

In their single-case study, Mohlman, Reed, Chazin, Ong, Georgescu, Tiu, et al. (2010) described the effects of a combined cognitive behavioural therapy (CBT) and executive skills training (attention process training) program on a 74-year-old male with Parkinson's disease and subjective complaints of excessive worry, short-term memory loss and word-finding difficulties. The subject lived independently in the community with his wife. A structured clinical interview was completed using the DSM-IV, diagnosing the subject with Generalized Anxiety Disorder. Despite his subjective complaints, the subject scored above average for his age and education on most neuropsychological pre-intervention tests [Mini-Mental Status Exam (MMSE), Boston Naming Test, Stroop Task, Controlled Oral Word Association Test (COWAT), and subtests from the Wechsler Adult Intelligence Scale (WAIS) (digit span forward, verbal paired associates, similarities)], with the exception of low average/average performance on non-verbal executive functions (digits backward and digit symbol from the WAIS, Trail Making B). The goal of treatment was to decrease anxiety and improve executive functions with ten weekly treatment sessions lasting 90-120 minutes each. The program included five sessions of CBT with interventions for cognitive restructuring, progressive muscle relaxation, and behavioural exercises, and five sessions of executive skills training with interventions targeted to improve sustained, selective, divided, and alternating attention, as well as to improve logical thinking. After each session, he was given home exercises related to that session's intervention topic. After intervention, the subject's anxiety had improved; he no longer had the diagnosis of Generalized Anxiety Disorder based on the result of a repeated structured clinical interview using the DSM-IV. His cognitive skills were unchanged, other than a slight improvement in non-verbal executive

functions. The subject felt that he maintained an improvement in both his mood and attentional control during the three-month follow-up period, which was corroborated by his wife. He also felt he was better able to cope with anxiety. Limited improvements in cognitive function were thought by the authors to be largely due to a ceiling effect of the assessment tools selected, since the majority of the subject's cognitive skills were above average pre-intervention. This study suggests there may be a potential for people with Parkinson's disease to improve their cognitive performance after cognitive rehabilitation, at least for non-verbal executive functions. Although the subject reported that cognitive gains were maintained over time, it is uncertain if an objective measure would demonstrate similar results since an objective measure of cognition was not used during the three-month follow-up period. The probable ceiling effect, single-subject sample size, and lack of a control comparison prevent the generalizability of this study. The subject was self-selected from a support group after reading a flyer, requiring the subject to be motivated to participate in support groups and research studies, and able to read English. It is possible that the subject's anxiety and need to seek re-assurance also made him more likely to self-select for the study and to respond favourably to any therapy provided. It is also possible that the improvement in the subject's anxiety had an indirect effect on his own experience of his cognitive function.

2.1.2 Two Convenience Sample Studies Without Control Groups

2.1.2.1 Sinforiani et al., 2004

Sinforiani, Bancheri, Pacchetti, & Sandrini (2004) published the first known study of cognitive rehabilitation in Parkinson's disease. In their study trial, the effect of cognitive training on a convenience sample of 20 participants with Parkinson's disease, without severe cognitive impairment or dementia (as determined by the authors using a battery of neuropsychological

tests only, without clinical observation or self-report from participants), who were attending a day hospital program was examined. Subjects participated in a cognitive rehabilitation program for one hour, twice weekly, for six weeks. Each session was followed by a motor rehabilitation session. Cognitive rehabilitation was done using a computer software program to stimulate cognitive functions of attention, abstract reasoning, and visuospatial skills at varying levels of complexity. At the end of twelve treatment sessions, participants performed significantly better in neuropsychological assessments of word fluency (phonological word fluency test or FAS), immediate and delayed memory for problem-solving (Babcocks story), and visuospatial reasoning (Raven's matrices) than pre-intervention. Gains were maintained when re-tested six months post-intervention. Although the significant improvements in cognitive function measured after intervention are promising, the study result is limited in its generalizability by its small sample size, sample of convenience, and lack of control group. Also, no measurements of occupational performance were taken, therefore the effect of the intervention on occupational performance in meaningful activities is not known.

2.1.2.2 Mohlman et al., 2011

In 2011, Mohlman, Chazin, & Georgescu followed up their 2010 single-case study with a study of cognitive training in a non-randomized sample of 16 participants with Parkinson's disease (ten males and six females). Participants ranged in age from 50 to 75, had self-reported difficulties with working memory, problem solving, and organization, did not have dementia (as defined by the authors using a cutoff score of a minimum of 24/30 on the Mini Mental Status Exam), and lived independently in the community. Participants were recruited via flyers, newsletter ads, and physician referrals from Parkinson's disease support groups. The authors

sought to determine the feasibility and participant acceptance of cognitive training program approaches, since cognitive training typically requires intensive practice, sustained effort, and persistence from participants in order for benefits to be achieved (Mohlman, Chazin, & Georgescu, 2011). An attention process training program was provided in four 90-minute sessions over four weeks. The training program provided one-to-one training with practice exercises and worksheets that targeted four types of attention (sustained, selective, alternating, and divided) in increasing complexity. Daily home exercises were also given for each participant. Post-intervention, the subjects improved on four tests of executive functions compared to pre-intervention (Digits Backward, Stroop test, Trails B, COWAT). After completion of the treatment program, participants in the study showed a high degree of acceptance and successful engagement in the program, as measured by self-ratings on a 6-point Likert-type scale measuring perceived fatigue, effort, progress, and enjoyment. Participants' ratings of enjoyment of the training tasks did not correspond to task difficulty. Self-ratings of participant progress varied across tasks according to difficulty level. Self-ratings of participant progress were also positively correlated with improvement in executive functions as measured post-intervention. This study is unique among examinations of the effects of cognitive training in Parkinson's disease in that it evaluated participants' subjective acceptance of a training program. Although this study was successful in demonstrating the feasibility and acceptance of a cognitive training program, the generalizability of the results are limited due to lack of a control group and small sample size that was not representative of the general population of people with Parkinson's disease (participants were non-demented, mostly well-educated white males with high income levels). Because of few outcome measures, conclusions regarding the effectiveness of the intervention are limited (Calleo, Burrows, Levin, Marsh, Lai, & York, 2012). Since there

was no long-term follow-up, it is not possible to determine if post-intervention gains were maintained over time.

2.1.3 Two Non-Randomized Controlled Trials

2.1.3.1 Nombela et al., 2011

Nombela, Pedro, Bustillo, Castel, Sanchez, Medina, et al., (2011) completed a non-randomized controlled trial to determine if cognitive training would improve the performance of participants in an attention task and restrict the extent of brain activation as measured by functional Magnetic Resonance Imaging (fMRI). Based on findings from previous investigators (Bench, et al., 1993; Hadland, Rushworth, Passingham, Jahansahi, & Rothwell, 2001; Fera, et al., 2007), Nombela et al. (2011) hypothesized that brain activation patterns observed when completing a Stroop task would be distributed over a wider area in participants with Parkinson's disease than in control participants pre-intervention due to imprecision of activation patterns related to cognitive deterioration, and that brain activation patterns in participants with Parkinson's disease may become more restricted post-intervention. Ten right-handed participants with Parkinson's disease between age 50-80, without tremor, dyskinesia, or substantial motor impairment were compared to ten healthy controls. Potential participants unable to correctly use their index finger for tapping tasks were excluded. Five of the ten participants with Parkinson's disease were self-selected to participate in cognitive training. The five remaining participants with Parkinson's disease and the ten healthy controls were not given training. As opposed to most other studies of cognitive training programs, the presence of dementia was not used as an exclusion criterion, although no participants scored below 25/30 on the MMSE (scores below 23/30 on the MMSE are considered to be indicative of dementia, while scores equal to or above

26/30 on the MMSE are considered to be within normal range [Folstein, Folstein, & McHugh, 1975; Mungas, 1991]). The MMSE scores for both groups of participants with Parkinson's disease were significantly lower than the MMSE scores for healthy subjects ($\bar{X}_{\text{control}} = 29.78 \pm 0.22$ vs. $\bar{X}_{\text{trained-PD}} = 26 \pm 0.41$ vs. $\bar{X}_{\text{untrained PD}} = 25.75 \pm 0.25$; $p \leq 0.001$). The five individuals with Parkinson's disease who participated in cognitive training were given "easy level" (Nombela et al., 2011, p. 84) Sudoku exercises that challenge working memory, attention, and problem-solving. The Sudoku-based cognitive training program was completed at home by participants daily for six months. A trained psychologist checked each participant's Sudoku blocks at weekly meetings to give corrections and explain errors. Participants were tested pre- and post-intervention using a modified Stroop task (printed words of congruent and incongruent items) while undergoing fMRI. Study results found improved reaction times, improved number of correct answers, and decreased number of missing answers on the Stroop task for individuals with Parkinson's who had completed the Sudoku exercise training program. fMRI findings pre- and post-intervention showed that trained participants with Parkinson's disease had restricted cortical activation patterns, in comparison to untrained participants with Parkinson's disease, that were comparable to the activation patterns observed in control participants. Nombela's study was the first known published investigation using neuroimaging evidence to measure brain activation as an indicator of the effects of cognitive training in Parkinson's disease. It was also the first known study of the potential of a popular leisure activity (and the first known study of the potential for Sudoku exercises specifically) to be used in cognitive training. The findings of this trial are strengthened by the intensity of its intervention over a long training period. The use of a popular leisure activity for cognitive training likely improves participant enjoyment and

acceptance of such an intense, long-term program, and may also help to generalize trained skills more easily to meaningful occupations. Unfortunately, no measures of occupational performance were taken, therefore the effects of the treatment intervention on occupational performance in meaningful activities is not known. The generalizability of the conclusions of this study is limited by its small, non-representative, non-randomized sample size. As the authors note, their strict exclusion criteria made selection of the Parkinson's disease participant group very difficult. The fact that participants volunteered for training could have resulted in participants that were more cognitively intact or that were more familiar with Sudoku choosing to complete the training compared to the group that did not participate in training.

2.1.3.2 Naismith et al., 2013

Naismith, Mowszowski, Diamond, & Lewis (2013) completed a controlled trial to examine the efficacy of a cognitive training program consisting of components in psychoeducation and computer-based cognitive training exercises on individuals with Parkinson's disease. Citing the promising study results from Sinforiani et al. (2004), Mohlman et al. (2011), Sammer et al. (2006), Paris et al. (2011), and Nombela et al. (2011), Naismith et al. (2013) hypothesized that their intervention program would result in improved memory and general cognition in the participants, as well as improved knowledge of factors related to healthy brain aging. Fifty participants with Parkinson's disease who were over the age of 50 were recruited from a Parkinson's disease research clinic. Participants were required to be on stable medication regimens for at least 6 weeks prior to enrollment in the study, to have adequate English language skills to participate in the study, and to be willing to attend therapy twice weekly for seven weeks. Potential participants with history of stroke or transient ischemic attack,

dementia (according to clinical diagnostic criteria established by Emre, Aarsland, Brown, et al., 2007), other neurological disorders, head injury with loss of consciousness equal to or greater than 30 minutes, medical conditions known to affect cognition, and psychiatric illnesses were excluded from the study. Participants were consecutively allocated into a group that received immediate treatment or a control group who waited at least seven weeks prior to beginning the same treatment. Thirty-five participants were allocated to the treatment group, while 15 remained in the wait list control group. All assessments were completed within two weeks of group allocation and completion of treatment. The intervention was provided in a group format with under ten participants in each treatment group. Participants attended two 2-hour sessions per week over a seven-week period. One hour of each session consisted of a psychoeducation group that promoted knowledge related to healthy brain aging, while the other hour of each session consisted of computer-based educational and commercially available cognitive training programs that were individualized according to participants' prior neuropsychological baseline test results. After completion of the treatment program, statistical analysis demonstrated improvements in performance on tests of learning and memory retention (the Logical Memory subtest of the Wechsler Memory Scale-III: the LOGMEM-I, and the LOGMEM-II) that were associated with the cognitive training and corresponded with moderate to large effect size improvements. No treatment effects were found on tests of cognitive processing speed (the Trail-making Test Part A), mental flexibility (the Trail-Making Test Part B), or verbal fluency (the Controlled Oral Word Association Test [COWAT]). A medium effect size improvement was found in improvement in knowledge related to healthy brain aging. At the time this study was published, it was the largest investigation to date on the effects of a cognitive training program on memory in individuals with Parkinson's disease. The study results were promising, but the study design did not make it

possible to distinguish between the effects of the psychoeducation group versus the cognitive training program. Because the study focused primarily on treatment effects on memory, effects of treatment on many other cognitive functions are not known. No measures of occupational performance were taken, therefore the effect of the intervention on occupational performance in meaningful activities is not known. The long-term effects of the intervention provided are not known due to lack of long-term follow-up, and the generalizability of the study results are limited by its non-randomized sample.

2.1.4 Nine Randomized Controlled Trials

2.1.4.1 Sammer et al., 2006

Sammer, Reuter, Hullman, Kaps, & Vaitl published the first known randomized controlled trial on the effects of cognitive training in Parkinson's disease in 2006; the trial was not blinded. 26 participants with Parkinson's disease were recruited from an in-patient rehabilitation hospital that specializes in treating Parkinson's disease. Cognition was assessed with neuropsychological testing of executive functions (Behavioral Assessment of the Dysexecutive Syndrome or "BADs", Cognitive Estimation Test TKS, Trails-Making ZVT), working memory (face-name learning test), and attention (Alters-Konzentrations-Test) at the beginning and end of their three-to-four week hospitalization. Twelve participants were randomly assigned to an executive function treatment group, while the 14 remaining participants were assigned to a standard treatment control group. Pre-morbid intelligence, mood, age, dopaminergic medications, and disease severity were all controlled for in analysis. The treatment group received ten 30-minute sessions of cognitive training over the length of their hospital stay, as well as standard treatment: occupational therapy, physiotherapy, and "physical

treatment” (Sammer, Reuter, Hullmann, Kaps, & Vaitl, 2006, p.116) (the authors did not explain what physical treatment is). The cognitive training consisted of a set of working memory tasks requiring executive functions, including problem-solving patterns, picture arrangement and completion tasks, block design, puzzle assembly, and storytelling. The control group received only the standard treatment. Study results showed improved performance of the cognitive training group in tasks associated with core executive functions (rule shift, task organization, and task switching), while no improvement was seen in the control group. Performance on working memory tasks declined in the control group but was maintained in the cognitive training group post-intervention. This study provided the first evidence that short, specific cognitive training improves some components of executive functions in people with Parkinson’s disease. The authors concluded that the specificity of the cognitive training on executive functions is supported by the fact that other cognitive functions such as attention were not improved by the cognitive training or by the non-specific standard treatment (Sammer, Reuter, Hullmann, Kaps, & Vaitl, 2006). The random allocation of participants to each of the two study groups strengthens the internal validity of the study, but the strength of the study is limited by the lack of blinding of either the participants or the study evaluators to the treatment conditions. The generalizability of the study results is limited by both the small sample size and the use of only in-patient participants. No measures were taken of occupational performance either pre- or post-intervention, therefore the impact of cognitive training on occupational performance in meaningful activities is not known. No long-term follow-up was done, therefore the long-term effects of treatment are not known.

2.1.4.2 Paris et al., 2011

Paris, Saleta, Maraever, Silvestre, Freixa, Torellas, et al., (2011) published a single-blind randomized controlled study of the efficacy of cognitive training in Parkinson's disease with the goal of overcoming the methodological limitations in the studies published by Sinforiani et al. (2004, no control group) and Sammer et al. (2006, random control but not blind). Paris et al. (2011) aimed to determine the efficacy of a cognitive training program on cognitive performance ("cognitive performance" is Paris et al.'s term) and health-related quality of life in participants with Parkinson's disease without dementia. Twenty-eight participants age 50-80 with Parkinson's disease that were not receiving any other cognitive, psychological, speech, or physiotherapy during the study period were recruited. Although participants with significant cognitive impairment were excluded (potential participants with MMSE scores <23/30 were excluded), 14 of the 28 participants met the authors' diagnostic criteria for mild cognitive impairment (a loss of more than 1.5 standard deviations on any cognitive test or subtest). Neither clinical observation nor self-report of cognitive decline were mentioned by the authors in their definition of mild cognitive impairment, nor was the interference of cognitive impairment with participants' functional independence levels, both of which are diagnostic criteria for PD-MCI according to the Movement Disorder Society Task Force Guidelines (Litvan, et al., 2012). Participants with below average pre-morbid intelligence, those on cholinesterase inhibitor medications or who had changes in their medications during the study period, those who did not complete at least 75% of the training program, those with major depression (Geriatric Depression Scale-15 score > 10), or those with severe auditory or visual deficits or another psychiatric/neurological diagnosis were excluded. Subjects were randomly assigned to either an experimental group (n = 16) or a control group (n = 12) using a matched pairs design, taking into account the variables of age and

vocabulary. The psychometric evaluator was blinded to the participants' group allocation. The treatment group received an individualized cognitive training program using interactive multimedia software, supervised by a trained clinical psychologist, as well as paper-and-pencil exercises. Training consisted of 28 activities designed to stimulate attention, working memory, memory, information processing speed, executive functions, visuospatial skills, and non-specific exercises. The control group received speech therapy group sessions. Both groups received 45-minute sessions three times per week over four weeks, as well as weekly home exercises and weekly individual tutored sessions. Results from pre- and post-intervention psychometric testing showed improved attention, working memory, information processing speed, immediate and delayed visual recall, visuospatial skills, verbal fluency, and executive functions. Assessments of health-related quality of life factors such as mood (GDS-15), cognitive difficulties in activities of daily living [Cognitive Difficulties Scale (CDS)], and basic and instrumental ADL functional status [(Parkinson Disease Questionnaire-39 (PDQ-39)] did not show any significant effect from treatment ($p = 0.90$ for GDS-15; $p = 0.81$ for CDS; $p = 0.15$ for PDQ-39.). Cognitive training had a larger effect on performance improvement of the participants with mild cognitive impairment than on participants without mild cognitive impairment on visuospatial skills and executive functions. This was the first known published blind randomized control trial on the effects of cognitive training in Parkinson's disease. As the authors state, the blind randomized control design ensures internal validity (Paris, et al., 2011). Although the sample size is small, it is largely representative of the general population of people with Parkinson's disease (representative gender proportion, mean age, mean disease duration, and mean years of education), except with the exclusion of people with dementia. Although this study did not include participants with Parkinson's disease and dementia, participants with Parkinson's disease

and mild cognitive impairment were included. The inclusion of participants with mild cognitive impairment allowed the study authors to demonstrate that subjects with mild cognitive impairment are capable of larger degrees of cognitive improvement with cognitive training than subjects without mild cognitive impairment. This difference was likely due to a ceiling effect in cognitively intact participants. The lack of change on health-related quality of life measures may be due to poor sensitivity of the measures used and lack of long-term follow-up. The authors postulate that the measures used to assess various aspects of health-related quality of life (mood, cognitive difficulties in ADLs, and ADL functional status) may not be sensitive enough to change and note that no specific measure of occupational performance exists that is sensitive to cognitive change in Parkinson's disease (Paris et al, 2011). No long-term measures were completed post-intervention, therefore long-term effects of cognitive training cannot be determined.

2.1.4.3 Edwards et al., 2013

Edwards, Hauser, O'Connor, Valdés, Zesiewicz, & Uz published a randomized controlled trial in 2013 examining the effects of cognitive speed of processing training in Parkinson's disease. Their study recruited participants from a movement disorder clinic and from several Parkinson's support groups. Potential participants were required to be over the age of 40, have a clinical diagnosis of idiopathic Parkinson's disease staged between 1-3 on the Hoehn & Yahr scale, and a stable medication regimen. Potential participants were excluded from the study if they had unpredictable or severe motor fluctuations or dyskinesias, an MMSE score below 24/30, or visual acuity below 20/80. 87 participants were recruited, all of whom were Caucasian and 74% of whom were male. The group had an average education of 15.36 years (SD = 8.3). 44

participants were randomly placed in the experimental group that completed speed of processing training, and 43 were randomized to the control group; neither the experimenters nor the participants were blinded as to treatment condition. Statistical analysis found that there were no significant differences in demographic characteristics or baseline measures between the experimental group and the control group. Participants in the experimental group were provided with “InSight” training software and instructions on how to install the software on their home computers. A research assistant contacted them within one week to ensure the software had been installed, and then contacted the participants again every two weeks to check on their progress with the software training. Participants were asked to aim to work on the training program for one hour three times per week for a total of twenty hours of training, but they were told that they could vary their training schedule based on their needs. They were also asked to focus every second training session specifically on the “Road Tour” exercise from the training program. Thirteen of the original group of 87 participants did not complete the study, therefore complete data from only 32 participants in the experimental group and 42 participants in the control group was available for analysis. In the experimental group, participants did not complete the study for the following reasons: one participant had a medication change; six participants stated they were too busy; one participant moved away; one participant had enrolled in another clinical trial; and three participants refused training and/or post-testing. In the control group, only one participant did not complete the study, and the reason given was that the participant had enrolled in another clinical trial. The study authors determined by statistical analysis that the participants lost to attrition were not significantly different in any demographic characteristics or baseline measures from the participants who remained in the study. Study results found that 69% of participants completed the recommended amount of training, with an average of 21.37 hours of total training

and an average of 10.01 hours of training specifically with the Road Tour exercise within the experimental group. The primary outcome measure used in the study was the Useful Field of View, which is a computer-administered evaluation of processing speed under gradually increasing cognitive demand for visual tasks. Results found that participants in the experimental group had significantly larger improvements in their Useful Field of View performance scores than the control group. Improvement in Useful Field of View scores was greater for participants in the experimental group who had longer disease duration, were a younger age at diagnosis, or who had higher levodopa medication equivalent doses. Study authors assert that a benefit of their training program is that it can be self-administered at home, therefore time and staffing costs are less than for other training programs, which is a valid argument in favour of such a training program. The authors hypothesize that, since the Useful Field of View predicts driving performance in Parkinson's disease, speed of processing training may delay the need for people with Parkinson's to stop driving. This study had the natural potential for evaluation of the effects of a cognitive intervention on occupational performance in a meaningful activity (driving), but unfortunately the study authors did not take this next step and evaluations of driving performance were not done. No other measures of the effects of the treatment intervention on occupational performance were done, therefore the effect of this intervention on occupational performance in any meaningful activity are not known. A strength of this study is that it had the largest participant group to date of any known published study that has examined cognitive training in Parkinson's disease, which can help support generalizability of the study results; however, the study sample included only highly educated, mostly male Caucasians, and therefore results cannot be generalized to individuals with Parkinson's disease who have lower education levels,

different ethnicities, or women. No long term follow-up was done, therefore the long-term effects of the treatment intervention are not known.

2.1.4.4 Cerasa et al., 2014

Cerasa, Gioia, Salsone, Donzuso, Chiriaco, Realmuto, Nicoletti, Bellavia, Banco, D'amelio, Zappia, & Quattrone published a double blinded, randomized controlled trial in 2014 examining the effects of a computerized attention and information processing training program on individuals with Parkinson's disease. Participants were recruited from an outpatient neurology clinic and needed to meet the following criteria: diagnosis of idiopathic Parkinson's disease; no presence of dementia; predominant deficits in either attention and/or information processing speed, working memory, and/or executive functioning; no impairment in other cognitive domains such as language and long-term memory; no presence of motor complications such as dyskinesias; no history of psychiatric problems; and no evidence of vascular brain lesions, brain atrophy, brain tumour, or movement artefacts on MRI scan. Twenty participants were enrolled in the study and were randomly allocated to either the experimental group (ten participants) or the control group (ten participants). Statistical analysis found that there were no significant differences in demographic characteristics or baseline measures between the experimental group and the control group. Participants and evaluators were blinded as to treatment conditions. Prior to the start of treatment, all participants completed neuropsychological assessments of spatial memory (Rey-Osterrieth Complex Figure Test), verbal memory (Selective Reminding Test), visuospatial processing (Judgment Line Orientation Test), verbal fluency (Controlled Oral Word Association Test), sustained attention and information processing speed (SDMT and PASAT), executive functions (digit span forward, digit span backward, Trails Making Test parts A & B,

Stroop test), depression (Beck Depression Inventory), anxiety (State-Trait Anxiety Inventory), and quality of life (Parkinson Disease Questionnaire-39). Both groups participated in twelve one-hour sessions over six weeks. The experimental group completed computerized attention ability and information processing task training using a computer program called “RehaCom,” while the control group completed a computerized visuomotor coordination tapping task. Five participants did not complete the study: two participants from the experimental group and three participants from the control group refused to continue treatment. The study authors do not report if the participants lost to attrition were significantly different in any demographic characteristics or baseline measures from the participants who remained in the study. At the end of six weeks, the 15 remaining participants repeated the measures that had been completed at baseline, as well as fMRI scans during which the participants were instructed to relax with their eyes closed, stay awake, and not move. When re-assessed after six weeks, significant improvements were found on the sustained attention and information processing speed measure (SDMT) and on the digit span forward measure in the experimental group. No significant changes were found on measures of depression, anxiety, or quality of life. Resting state fMRI showed functional reorganization of the dorso-lateral prefrontal cortex and the superior parietal lobule, which are both areas that the authors state are essential for executive functions. The double blinded, randomized controlled trial design strengthens the internal validity of this study’s findings, although the internal validity is less strong than it could be since no analysis of potential differences in demographic characteristics or psychometric parameters between the participants who were lost to attrition and those who remained in the study was done. The study is limited by its small sample size, which was largely due to the narrow inclusion/exclusion criteria set by the authors, and therefore the study’s findings cannot be generalized to other individuals with

Parkinson's disease. Although no significant changes in mood or quality of life were detected, the study intervention was not directed toward improving participants' performance in any particular activity that they may find meaningful, so lack of change in mood or quality of life is not surprising. No measures were taken of occupational performance either pre- or post-intervention; therefore, the impact of cognitive training on occupational performance in meaningful activities is not known. The long-term effects of the treatment intervention are not known, as no long-term follow-up was done.

2.1.4.5 Costa et al., 2014

Costa, Peppe, Serafini, Zabberoni, Barban, Caltagirone, & Carlesimo (2014) published a double blind randomized controlled trial examining the effects of a cognitive training program on set shifting ability in Parkinson's disease. To be considered for inclusion in the study, participants needed to have a diagnosis of idiopathic Parkinson's disease and mild cognitive impairment according to diagnostic criteria for PD-MCI established by Litvan et al. (2012). Participants could not have any major psychiatric diagnoses, any neurological diagnosis other than Parkinson's, vascular brain lesions, any other major systemic or metabolic condition that could affect cognition, any significant changes in routine activities of daily living, significant depression, or significant apathy. Healthy control participants were also recruited, and these participants needed to have an absence of any current or past neurological or psychiatric diagnoses, any other major systemic or metabolic conditions with the potential to affect cognition, no history of drug or alcohol abuse, no subjective cognitive impairments, and MMSE scores $\geq 26/30$. Seventeen individuals with Parkinson's disease with mild cognitive impairment and eight healthy controls were recruited, all of whom were right-handed. The study authors did

not indicate where participants were recruited from. Participants with Parkinson's disease were randomly assigned to one of two treatment arms, both of which consisted of twelve 45-minute treatment sessions over four weeks. Nine participants with Parkinson's were in the experimental group, and completed pencil and paper tasks in which they had to alternately choose between stimuli from different semantic categories or between stimuli with different spatial and visual features. Participants progressed through four training modules of increasing difficulty. When a participant did not reach 80% accuracy in any one module, that module was completed again. Eight participants with Parkinson's were in the placebo group, in which participants completed simple cognitive exercises focusing on language skills as well as respiratory exercises intended to improve their phonation. Pre- and post-intervention measures consisted of a prospective memory procedure; a verbal fluency test consisting of phonemic fluency, semantic fluency, and alternating phonemic/semantic fluency subtests; and the Trail Making Test parts A and B. The prospective memory procedure involved having participants seated in a dimly lit room approximately 40 cm from a computer screen on which text stimuli were presented, consisting of 32 trisyllabic, six-letter, singular words and 24 non-words created by replacing the first syllable with the last syllable of real words. Participants completed 48 trials in which they were asked to decide if the two pairs of words presented to them were real words or if one of the two was a non-word. In another set of 48 trials, participants were asked to decide if the middle syllable of two series of letters was the same or not. Participants responded by pressing one of two buttons on a keyboard. In addition, participants were also asked to press a different button whenever the syllables "fa" and "go" appeared at the middle of one of the series of letters forming the pair. Study results found that performance accuracy on the prospective memory procedure improved in the experimental group but not in the placebo group, but there was no difference in response

times on the prospective memory procedure between the two groups. Participants in the experimental group improved their performance on the alternating fluency task, but not on the phonemic or semantic fluency tasks. There was no significant change in the placebo group's performance on fluency tasks. Participants in the experimental group improved on the Trails B test, whereas no change was observed in Trails A or B test scores in the placebo group. Study results found that, within the participant population, set shifting and prospective memory were strongly associated with one another, and that prospective memory in individuals with Parkinson's disease and mild cognitive impairment can improve with set shifting training. The double blind, randomized controlled trial design of this study strengthens the internal validity of its findings. Unfortunately, study results cannot be generalized to the larger population of individuals with Parkinson's disease and mild cognitive impairment due to the small number of participants, and also because study authors did not indicate where their participants were recruited from. No measures were taken of occupational performance either pre- or post-intervention; therefore, the impact of cognitive training on occupational performance in meaningful activities is not known. The long-term effects of the treatment intervention are not known, as no long-term follow-up was done.

2.1.4.6 Peña et al., 2014

Peña, Ibarretxe-Billbao, García-Gorostiaga, Gomez-Beldarrain, Díez-Cirarda, & Ojeda published a singled blinded randomized controlled trial in 2014 examining the effects of a structured pencil and paper cognitive training program on cognition, clinical symptoms, and functional disability in Parkinson's disease. Participants needed to have a diagnosis of idiopathic Parkinson's disease, be between 45-75 years old, have a Hoehn & Yahr stage of 1 to 3, and have

no diagnosis of dementia or other neurological condition. Forty-two individuals were recruited from an outpatient neurology clinic and a Parkinson's support group and then randomly assigned to a cognitive training group (20 participants) or a control group (22 participants). Study evaluators were blinded as to each participant's group allocation, but participants were not blinded. The cognitive training program provided was "REHACOP," which consists of structured pencil and paper tasks with gradually increasing cognitive difficulty. Participants in the REHACOP program completed 60-minute group sessions three times per week for thirteen weeks. Four weeks of training focused on attention (sustained, selective, alternating, and divided attention), three weeks of training focused on memory (visual and verbal learning, recall, and recognition), three weeks focused on language skills (grammar, syntax, vocabulary, verbal fluency, verbal comprehension, and abstract language skills), two weeks focused on executive functions (planning, proverbs, analogies), and one week on social cognition (theory of mind, social reasoning, and moral dilemmas). Participants in the control group attended group sessions with the same frequency as the experimental group, where they completed "occupational group activities" such as reading the news, drawing, and constructing objects from paper or wood. The study authors used measures of cognitive processing speed (Trail Making Test – part A and Salthouse Letter Comparison Test), verbal memory (Hopkins Verbal Learning Test), visual memory (Brief Visual Memory Test), executive functions (Stroop test word-colour and interference scores), and theory of mind (Happé test) as primary outcome measures, and measures of neuropsychiatric symptoms (NPI-Q), apathy (Lille Apathy Rating Scale), and functional disability (WHO-DAS II) as secondary outcome measures. Post-treatment evaluations found significant improvements in processing speed, visual learning, visual memory, theory of mind, and functional disability in the experimental group as compared to the control group. No

improvement was found in executive functions, although the authors hypothesize that the reason for this discrepancy with findings from other studies that did show improvement in executive functions is that the authors of this study used only the Stroop colour-word and interference tests to measure executive functions, and that executive functions may have been more accurately measured using a different tool such as the Wisconsin Card Sorting Test or the Behavioural Assessment of the Dysexecutive Syndrome (BADS). The randomized controlled trial design of this study strengthens its internal validity, but the internal validity is weakened by the fact that study participants were not blinded as to their group allocation. This study is unique in relation to other published studies on cognitive training in Parkinson's disease in that it is the first study to include training on theory of mind; further study on the effects of cognitive training on theory of mind is needed to determine if the results of this study can be replicated. A strength of this study is that it is the third known study on cognitive rehabilitation in Parkinson's disease to evaluate the effect of cognitive training on functional disability; interestingly, it is the first study to find an improvement in functional disability (occupational performance) following a cognitive training intervention. The authors hypothesize that the reason improvement in functional disability was seen in participants in their study may be related to the nature of the REHACOP training itself, since strategic learning and transfer techniques are emphasized within this training program. Their hypothesis is a logical one, since no other study on cognitive training in Parkinson's disease published to date has provided an intervention with any focus on strategic learning or transfer techniques beyond the cognitive domains focused on during treatment. The long-term effects of the treatment provided in this study are not known, as no follow-up was done.

2.1.4.7 Petrelli et al., 2014 and Petrelli et al., 2015

Petrelli, Kaesbert, Barbe, Timmerman, Fink, Kessler, & Kalbe published a randomized controlled trial in 2014 examining the effect differences of structured versus unstructured cognitive training in Parkinson's disease. Sixty-five participants were recruited from an outpatient movement disorder clinic and from Parkinson's support groups. Potential participants with suspected dementia (MMSE scores <25/30), other neurological or psychiatric diagnoses (except depression), visual or hearing impairments, and Deep Brain Stimulation (DBS) were excluded. Participants who had medication changes between pre-intervention and post-intervention were excluded from post-intervention analysis. Participants were randomly assigned to one of three groups: 22 participants were allocated to a treatment group that received a structured cognitive multi-component training program known as "NEUROvitalis" in which treatment sessions focused on attention, memory, and executive function training; 22 other participants were allocated to a group that completed unstructured, non-domain-specific cognitive tasks in a program entitled "Mentally Fit"; the other 21 participants were allocated to a control group that received no treatment. Sessions for both the NEUROvitalis group and the Mentally Fit group were 90 minutes long and consisted of twelve sessions over six weeks. The study authors used tests of attention (Brief Test of Attention), verbal short-term and long-term memory (DemTect), visual long-term memory (Complex Figure), and executive functions (DemTect: digit span reverse; Semantic DemTect) as primary outcome measures, and tests of visuo-construction (Complex Figure), depression (Beck Depression Inventory-II), and quality of life (Parkinson Disease Questionnaire-39) as secondary outcome measures. Results found that working memory in the NEUROvitalis group improved, but not in the other two groups. Participants in the Mentally Fit group did not make any significant improvements in any

cognitive score compared to the treatment group. The authors attribute this difference to the hypothesis that participants with Parkinson's disease benefit more from cognitive training in which specific cognitive domains are trained in domain-focused sessions than from unstructured sessions. Only the participants in the Mentally Fit group improved on depression scores, which the authors attribute to the increased opportunities for social interaction in the Mentally Fit group, in which communication and group conversations were integral to the program, whereas there was less time for social interaction in the NEUROvitalis group. None of the three groups improved on the measure of quality of life. This study is unique in that it is the only study to date that has compared the effects of two different cognitive training programs for individuals with Parkinson's with each other and with a control group that received no treatment. The use of a control group allows for multiple comparisons to be made between the true effect of training versus non-training as well as the differences between two groups that received different types of training. The randomized controlled trial design of this study strengthens its internal validity, although the study authors did not indicate if either the participants or the evaluators were blinded as to group allocations. Although the overall sample size for this study was larger than the sample sizes in many other studies on cognitive training in Parkinson's disease, each of the three participant groups were rather small, therefore results cannot be generalized to the larger population of individuals with Parkinson's disease. In a follow-up article published in 2015, Petrelli et al. re-assessed 47 participants from their 2014 study to determine the long-term effects of their treatment intervention. The follow-up study found, interestingly, that participants in both cognitive training groups maintained their overall cognitive functional status one year following the intervention and their risk of developing mild cognitive impairment was reduced in comparison to the control group, which exhibited cognitive decline. These findings suggest that

the exact type of cognitive training provided may not be important in order to provide long-term benefits. Findings from this study are consistent with others that have completed long-term follow-up, both of which have found that gains made during cognitive training in Parkinson's disease can be maintained over the long-term (Mohlman et al., 2010; Sinforiani et al., 2004).

2.1.4.8 Zimmermann et al., 2014

Zimmermann, Gschwandtner, Benz, Hatz, Schindler, Taub, & Fuhr (2014) published a single-blinded randomized controlled trial comparing the effects of a cognition-specific computerized cognitive training program with a non-cognition specific motion-controlled computerized sports game on Parkinson's disease. Thirty-nine participants were recruited from an outpatient movement disorder clinic and from a Parkinson's support organization. Potential participants were excluded if they had a diagnosis of dementia or another severe neurological diagnosis. Participant randomization was restricted by controlling for age, gender, education level and group size (an allocation ratio of 1:1 was chosen). Participants were blinded as to their group allocation, but study evaluators were not blinded. Nineteen participants were allocated to a group that completed four training modules focusing on attention, working memory, planning and execution skills, and inhibition using a computerized cognitive training called "CogniPlus." Twenty participants were allocated to a group that played four different sports games (table tennis, swordplay, archery, and "air sports") on a Nintendo Wii game called Wii Sports Resort. Both groups completed each of their four training tasks for 10 minutes each in a fixed order, three times a week for four weeks. The effects of training were measured using tests of attention and working memory (Tests of Attentional Performance: alertness and working memory), cognitive flexibility (Trails Making Test – part A and B), visuo-construction (Block Design Test,

a component of the Wechsler Intelligence Test for Adults), and episodic memory (California Verbal Learning Test). Study results found that participants who were trained with the Wii Sports game improved in their attention scores more than the participants who were trained with the CogniPlus program, and that there were no other significant differences in level of improvement in other cognitive domains between the two groups. The study authors hypothesize that the reason for the larger improvement in attention scores in the group that was trained with the video game may be explained by other study findings that have shown that cognitive training combined with physical exercise has greater benefits than cognitive training alone (Reuter et al., 2012). The authors also hypothesize that one reason the group which completed cognition specific training did not perform better than the group which played video games may be because the improvements seen in cognition specific training are usually task specific, and may not be transferable or generalizable to other tasks. The authors recognize that this limitation is problematic clinically, and state that cognitive training should be intended to improve individuals' performance in meaningful activities. Although they recognized the importance of aiming for cognitive training to have a beneficial impact on individuals' performance in meaningful activities, the authors did not measure occupational performance either pre- or post-intervention, therefore the impact of cognitive training on occupational performance in meaningful activities is not known for either of the two participant groups. Since the Wii Sports video game simulates sports games that are enjoyable and meaningful to many individuals, it is possible that participants in the group that played the Nintendo Wii game had greater internal motivation to do well with training. For the same reasons, it is also possible that skills learned from playing the video game may have been transferrable to improved occupational performance in one or more of the "real world" versions of these sports games. The single-blinded

randomized controlled design of this study strengthens its internal validity, but its validity is weakened by the fact that the evaluators were not blinded as to treatment conditions. Two other limitations the authors recognize in their study is that, since neither a non-treatment control group nor a healthy control group were included, the absolute effect of the interventions provided to each participant group is not known, nor is it known what the typical learning effects of treatment would have been in the general population. No long-term follow-up was done, therefore the long-term effects of the interventions provided to each participant group are not known.

2.1.4.9 Angelucci et al., 2015

In 2015, Angelucci, Peppe, Carlesimo, Serafini, Zabberoni, Barban, Shofany, Caltagirone, & Costa published a double blinded randomized controlled pilot study examining the effects of a pencil-and-paper set shifting training program on executive functions and on brain derived neurotrophic factor (BDNF) blood serum levels. Fifteen right-handed participants with idiopathic Parkinson's disease participated in the study; the authors did not explain their recruitment methods. Potential participants were included if they had mild cognitive impairment according to the diagnostic criteria for PD-MCI established by Litvan et al. (2012). Measures of depression and apathy were administered but were not used as exclusion criteria. Seven participants were randomly assigned to the treatment group while eight participants were randomly assigned to the placebo group. Participants were blinded as to which group they were assigned, as were the evaluators. There were no statistically significant differences between reported demographic or clinical features between the two participant groups; however, gender was not included in the demographic characteristics described by the authors. A

neuropsychological test battery was administered to each participant, consisting of assessments of verbal memory (immediate and delayed recall of a 15-word list, prose recall), visuo-construction and visual memory (Rey figure drawing, Copy of Drawings and Copy of Drawings with Landmarks), attention and short-term memory (digit span and Corsi block tapping test forward and backward, Trail Making Test – Part A), executive functions (phonological word fluency, Modified Card Sorting Test, Raven’s Matrices, Trail Making Test – Part B), and language (Objects and Verbs Naming subtests from the Neuropsychological Examination of Aphasia), but the purposes of these tests were not explained and results were not provided. Participants in both groups received twelve 45-minute treatment sessions over a one month period, occurring three times weekly. The experimental group completed paper-and-pencil set shifting training exercises that required participants to alternately choose between stimuli from different semantic categories (for example, to choose between figures representing living or non-living objects) or choose between stimuli with different visuospatial characteristics (for example, choose stimuli on an arrow that are alternately close to or far from a target letter). The training exercises were grouped into four modules of increasing difficulty. Modules were repeated until participants achieved at least 80% accuracy before progressing to the next module. Participants in the placebo group completed language and sustained attention exercises (reordering of sentence sequences and dictation exercises) without any progression of difficulty, and respiration exercises. Treatment effects were measured using the Zoo Map Test (a measure of executive function, specifically planning skills) of the Behavioral Assessment of the Dysexecutive Syndrome (BADS) battery and blood serum sampling of brain-derived neurotrophic factor (BDNF). Participants in the experimental group showed a statistically significant improvement in performance on the Zoo Map Test and a statistically significant increase in BDNF serum levels,

while participants in the placebo group did not show statistically significant changes in either Zoo Map Test performance or BDNF serum levels. Angelucci et al.'s results showing improved performance on tests of executive function are consistent with findings from prior studies on the effects of cognitive rehabilitation in Parkinson's disease. Uniquely, this study appears to be the first to demonstrate that cognitive rehabilitation may increase BDNF serum levels, suggesting that BDNF serum levels may show the first known biomarker of the effects of cognitive rehabilitation. The internal validity of this study is strengthened by its double blind randomized controlled design, but the generalizability of the results are limited by its small sample size, non-disclosure of study participants' genders, and non-disclosure of recruitment methods. No measures were taken of occupational performance either pre- or post-intervention; therefore, the impact of cognitive training on occupational performance in meaningful activities is not known. No long-term follow-up was done, therefore the long-term effects of treatment are not known.

2.1.5 Summary

Although studies are still few and sample sizes have mostly been small, the number of studies on the effects of cognitive rehabilitation for people with Parkinson's disease and cognitive impairment has been growing more rapidly in recent years, the quality of evidence is growing more robust, and most findings are encouraging. Particularly over the last twelve years, cognitive rehabilitation has been increasingly acknowledged as a beneficial non-pharmacological treatment for cognitive impairment in Parkinson's disease (Calleo, 2012; Hindle et al., 2013; Leung et al., 2015). Of the fourteen studies published to date (not including Petrelli et al.'s 2015 follow-up study), all but the single case study by Molhman et al. (2010) and the randomized controlled trial by Zimmermann et al. (2014) showed improvements in neuropsychological skills

such as processing speed, verbal fluency, learning, memory retention, working memory, visuospatial reasoning, and executive functions (for example, rule shift, task organization/planning, and task switching) with cognitive training (Angelucci et al., 2015; Cerasa et al., 2014; Costa et al., 2014; Edwards, Hauser, O'Connor, Valdés, Zesiewicz, & Uc, 2013; Mohlman, Chazin, & Georgescu, 2011; Naismith, Mowszowki, Diamond, & Lewis, 2013; Nombela, et al., 2011; Paris, et al., 2011; Peña, Ibarretxe-Bilbao, García-Gorostiaga, Gomez-Beldarrain, Díez-Cirarda, & Ojeda, 2014; Petrelli et al., 2014; Sammer, Reuter, Hullmann, Kaps, & Vaitl, 2006; Sinforiani, Banchieri, Pacchetti, & Sandrini, 2004). The only three studies that took measures at long-term follow-up were able to show maintenance of intervention results for several months post-intervention, but only one of these studies had a control group (Petrelli et al., 2014 & 2015), and both of the other studies (Mohlman et al., 2010; Sinforiani et al., 2004) were small. Overall, very little is yet known about the long-term effects of cognitive rehabilitation in Parkinson's disease and more research is needed in this area.

Despite the encouraging findings so far, very little is known about the effects of cognitive rehabilitation on health-related quality of life or occupational performance in people with Parkinson's disease and cognitive impairment. Of all fourteen unique studies, only Paris et al. (2011) and Petrelli (2014) attempted to measure the effects of cognitive rehabilitation on health-related quality of life factors, and both groups of authors found no effect of cognitive rehabilitation on health-related quality of life. Both Paris et al. (2011) and Peña et al. (2014) examined occupational performance in activities of daily living, with conflicting findings: the measures used by Paris et al. showed that cognitive rehabilitation had no effect on occupational performance; Peña et al. (2014) were able to demonstrate that cognitive rehabilitation can

improve occupational performance in meaningful activities, and attributed this improvement to the strategic learning and transfer techniques that were emphasized within the training program that they provided. Paris et al. (2011) acknowledge that, although their study was unable to demonstrate change in health-related quality of life or occupational performance, there is a great need for individualized cognitive rehabilitation programs that are provided in realistic settings to encourage translation of training to improve occupational performance in both basic and instrumental activities of daily living. This need and the link between cognitive status and occupational performance is supported by Disbrow et al. (2012), Foster & Hershey, (2011), Korts, van Bilen, Tuch, Leenders, & Brower, (2011); Pyun, Yang, Lee, & Yook, (2009), Rosenthal et al. (2010), and Ventura et al., (2015). The Cognitive Orientation to daily Occupational Performance (CO-OP) has the potential to be an ideal cognitive rehabilitation program for individuals with Parkinson's disease and cognitive impairment because it is individualized by design, provides task-based training in realistic environments, aims to generalize trained skills to functional tasks completed outside of treatment sessions, and also aims to transfer trained skills to untrained functional tasks (Dawson, Gaya, Hunt, Levine, Lemsky, & Polatajko, 2009; Polatajko, Green, & Bernie, 2013; Polatajko & Mandich, 2004).

2.2 Summary of the Literature on the Cognitive Orientation to daily Occupational Performance (CO-OP)

The CO-OP is a meta-cognitive task-oriented problem solving strategy originally designed as a motor-learning intervention for children with developmental coordination disorder (Polatajko, Green, & Bernie, 2013; Polatajko & Mandich, 2004). It teaches individuals to monitor and regulate their own behaviour using a "Goal- Plan- Do- Check" strategy for self-

selected tasks with guidance from a clinician (Polatajko & Mandich, 2004) and has been extensively studied in the pediatric population (Polatajko, Green, & Bernie, 2013; Polatajko & Mandich, 2004). Since the 1990's, evolving research evidence has led a shift in treatment interventions for children with developmental coordination disorder from process-oriented "bottom-up" micro-level approaches toward task-oriented "top-down" macro-level approaches (Polatajko, Green, & Bernie, 2013). Evidence has shown that deficit-oriented approaches with children with development coordination disorder are "at best... no better than other approaches that are less labour intensive," (Sugden, 2007, p. 469) and are "grounded in out-dated models of how movements are controlled and learned" (Sugden, 2007, p.469). The evidence shows that alternatively, task-oriented approaches "report the highest effects," (Sugden, 2007, p. 469). In comparison to all other task-oriented treatment approaches in children with developmental coordination disorder, the CO-OP approach has been found to be superior (Chen & Cohn, 2003). Although the largest body of evidence supporting the effectiveness of the CO-OP is for children with developmental coordination disorder (Polatajko, Green, & Bernie, 2013), promising results have also been found with children with cerebral palsy (Mandich, Polatajko, & Zilberbrant, 2008), acquired brain injury (Missiuna, et al., 2010), attention deficit hyperactivity disorder (Simpson & Mandich, 2007), and Asperger's syndrome (Rodger & Brandenburg, 2009).

In recent years, the applicability of the CO-OP has been explored in adult populations. McEwen, Polatajko, Huijbregts, & Ryan, (2009, 2010), Henshaw, Polatajko, McEwen, & Ryan, (2011), Polatajko, McEwan, Ryan, & Baum (2012) and McEwen et al. (2015) have found encouraging results of the effects of the CO-OP on motor skill performance training with adults

ranging from < 3 months to 40 months post-stroke, but none of these studies focused directly on improvement of occupational performance issues related to cognitive impairment.

Five other studies are known to have been published on the applicability of the CO-OP with adults, all of which examined the potential of the CO-OP to improve occupational performance issues related to cognitive impairment. Three studies evaluated participants with impairment in executive functions following chronic traumatic brain injury (Dawson, Gaya, Hunt, Levine, Lemsky, & Polatajko, 2009; Dawson, Binns, Hunt, Lemsky, & Polatajko, 2013; Ng, Polatajko, Marziali, Hunt, & Dawson, 2013). Another study evaluated a single participant with impairment in executive functions due to acute stroke (Skidmore, Holm, Whyte, Dew, Dawson, & Becker, 2011), and the most recently published study evaluated participants with impairments in executive functions due to stroke within the previous twelve months (Poulin, Korner-Bitensky, Bherer, Lussier, & Dawson, 2016). As with the studies examining the effects of the CO-OP on motor skill performance training in adults, the studies examining the effects of the CO-OP on challenges related to impaired executive functions have had promising results.

The literature on use of the CO-OP in both adult and pediatric populations has shown the CO-OP can be a beneficial treatment strategy for attainment of self-selected occupational performance goals (Chen & Cohn, 2003; Henshaw, Polatajko, McEwen, & Ryan, 2011; Mandich, Polatajko, & Zilberbrant, 2008; McEwen, Polatajko, Huijbregts, & Ryan, 2009, 2010; Missiuna, et al., 2010; Polatajko, Green, & Bernie, 2013; Polatajko & Mandich, 2004; Simpson & Mandich, 2007; Rodger & Brandenburg, 2009). No known risks to participating in the CO-OP are mentioned in the literature.

Haskins has established practice standards for meta-cognitive strategy training for executive dysfunction (Haskins, 2012, as cited by Polatajko, Greene, & Bernie, 2013), which emphasize internalized awareness and control over one's own behaviour. Haskins' meta-cognitive strategy training program aims to develop and enhance control of cognitive processes and remove cognitive, emotional, and behavioural obstacles that inhibit cognitive processes by teaching problem-solving strategies such as the Framework to Improve Performance, and "Goal-Plan-Do-Review," which is very similar to the CO-OP's "Goal-Plan-Do-Check" strategy (Haskins, 2012).

To date, no task-based cognitive strategy treatment approach has yet been studied with individuals with Parkinson's disease and cognitive impairment. When considering the populations studied thus far using the CO-OP as a treatment intervention, individuals with impaired executive functions in the chronic phase of traumatic brain injury and individuals with Parkinson's disease and mild cognitive impairment have similar patterns of chronic cognitive impairment. Since there is emerging evidence on the effectiveness of the CO-OP for individuals with cognitive impairment related to chronic brain injury, it would stand to reason that the CO-OP has the potential to be an effective treatment tool to improve performance in daily occupations for individuals with Parkinson's-related cognitive impairment.

The CO-OP is "a client-centred, performance-based problem solving approach that enables skill acquisition through a process of strategy use and guided discovery," (Polatajko & Mandich, 2004, p. 2). It is designed to teach individuals to generalize strategies learned to daily life activities, and is unique in that clients set their own goals, which is fundamental to client-centred practice (Polatajko, Green, & Bernie, 2013). The CO-OP emphasizes training individuals

to use verbal self-instruction in order to eventually internalize the strategy (Polatajko & Mandich, 2004). Although best practice guidelines for implementation of the CO-OP in pediatric populations are to address three client-chosen goals over 12 one-hour long treatment sessions, no best practice guideline yet exist for the adult population (Polatajko, Green, & Bernie, 2013).

The original authors of the CO-OP recommend that individuals applying the protocol are experienced occupational or physiotherapists that have been trained in the protocol by attending a 16-hour CO-OP workshop presented by a certified instructor (Polatajko & Mandich, 2004), and have read Polatajko & Mandich's 2004 publication: "Occupation in Children: The Cognitive Orientation to daily Occupational Performance (CO-OP) Approach. Therapist certification began being provided in 2013, and requires direct demonstration of knowledge and competency in administration of the CO-OP to a certified CO-OP instructor (CO-OP Academy, 2015). The principal investigator of this study attended a 16-hour CO-OP workshop presented by certified instructors in May, 2013 (Polatajko, Green, & Bernie, 2013), but is not a certified CO-OP therapist.

2.2.1 The Five Key Components of the CO-OP

The CO-OP treatment protocol is thoroughly described in detail by Polatajko, Green, & Bernie (2013) and Polatajko & Mandich (2004). Dawson et al. (2009) have summarized the CO-OP into five key components:

1. Participants are involved in choosing their own individual treatment goals to maximize the likelihood that they will stay motivated and engaged in the three phases of the CO-OP strategy (Dawson, Gaya, Hunt, Levine, Lemsy, & Polatajko, 2009):

- a. Acquisition of strategy
- b. Generalization (to same tasks but outside of treatment session)
- c. Transfer to other goals

(Dawson et al., 2013; Polatajko & Mandich, 2004)

2. Intervention is based on “dynamic performance analysis” Polatajko & Mandich, 2004, p. 60) by the clinician of problems or breakdowns in performance, much like traditional activity analysis in occupational therapy (person-environment-occupation) (Dawson, Gaya, Hunt, Levine, Lemsy, & Polatajko, 2009; Polatajko, Green, & Bernie, 2013; Polatajko & Mandich, 2004).
3. Cognitive strategies are used to structure development of the client’s actual performance skills toward the treatment goal using a global problem-solving approach: “Goal- Plan- Do- Check” (Polatajko & Mandich, 2004, p. 68).
4. Unique to the CO-OP, clinicians provide “guided discovery” (Polatajko & Mandich, 2004, p. 80) for participants to find effective strategies to overcome their task performance difficulties. Dawson, Gaya, Hunt, Levine, Lemsy, & Polatajko (2009) cite evidence that the individual’s participation in finding their own effective strategies is integral to the success of the intervention.
5. The CO-OP encourages the participant’s significant other to observe treatment sessions and to help reinforce the “Goal- Plan- Do- Check” (Polatajko & Mandich, 2004, p. 68) strategy in everyday challenges the participant wishes to improve upon.

The CO-OP training workshop teaches that typically 60% of total therapy time is spent on the three sub-components of the plan: dynamic performance analysis, guided discovery, and domain-specific strategies (Polatajko, Green, & Bernie, 2013).

2.2.2 Use of the CO-OP to Address Cognitive Impairment in Adult Populations

To date, five published studies are known to have examined the effect of the CO-OP on adults with cognitive impairment. All five studies addressed impairments in executive functions specifically, and are summarized in the table on the following page.

Table 2.2 Summary of Literature Review on Use of the CO-OP to Address Cognitive Impairment in Adult Populations

Authors	Year	Study Design	Total N	Diagnosis	Intervention	Intervention Frequency	Outcome Measures	Results
Dawson et al.	2009	Single-case pilot study	3	Chronic TBI	CO-OP	Twenty one-hour sessions twice weekly over ten weeks	COPM, Dysexecutive Questionnaire (DEX)	Participant self-report of improved performance and satisfaction on 7 of 9 trained goals and 4 of 7 untrained goals; results maintained at 3-month follow-up
Skidmore et al.	2011	Single-case pilot study	1	Acute CVA	CO-OP	Ten 45-minute sessions for five days/week over two weeks	COPM, Functional Independence Measure (FIM), Performance Assessment of Self-Care Skills (PASS)	Participant self-report of improved performance and satisfaction on 8 of 8 trained goals; untrained goals not measured; independence with ADLs improved; no long-term follow-up
Dawson et al.	2013	Single-Blinded Partially randomized controlled trial	13	Chronic TBI	CO-OP treatment group (N = 7) Control group (N = 6)	Two one-hour sessions per week for ten weeks	COPM, Dysexecutive Questionnaire (DEX), Mayo-Portland Adaptability Inventory-Participation Index (MPAI-4-P), Assessment of Motor and Process Skills (AMPS)	Participant self-report of significantly more improved performance and satisfaction on untrained groups in the experimental group than in the control group; improved community integration in the experimental group
Ng et al.	2013	Single-case pilot study	3	Chronic TBI	CO-OP	Two one-hour sessions per week for ten weeks via Skype	COPM, DEX, MPAI-4-P	Participant self-report of improved performance and satisfaction in trained and untrained goals; fewer symptoms of executive dysfunction; greater community integration
Poulin et al.	2016	Partially randomized pilot study	11	Sub-acute CVA	CO-OP treatment group (N = 6) Computer based training treatment group (N = 5)	Two one-hour sessions per week for eight weeks	COPM; three tests of executive functions (Trails Making Test, Colour-Word Interference Test from D-KEFS, Digit Span); Assessment of Life Habits; Self-Efficacy Scale for Performing Life Activities Post-stroke; DEX	Participant self-report of improved performance and satisfaction in trained and untrained goals for both treatment groups; report from significant others of improved performance for both treatment groups; improvement in executive functions in both groups; greater improvement in self-efficacy and further reduced impact of executive function impairments in everyday life for CO-OP treatment group compared to computer based training group; results maintained at follow-up

2.2.2.1 Dawson et al., 2009

In 2009, Dawson, Gaya, Hunt, Levine, Lemsky, & Polatajko published a single-case pilot study to test the applicability of the CO-OP for adults with executive dysfunction arising from traumatic brain injury. Three adults 5-20 years post-TBI and their significant others participated in the study. The intervention guided participants to use a meta-cognitive problem-solving strategy to perform self-identified goals. The CO-OP treatment protocol was provided in participants' own environments as much as possible over a total of 20 one-hour sessions that occurred twice weekly and addressed a total of 9 trained goals and 7 untrained goals for each participant. Dawson et al.'s study findings showed that performance on self-identified goals improved to criterion on 7 of 9 trained goals and on 4 of 7 untrained goals; improvement was maintained after 3-month follow-up. Participants and their significant others reported positive treatment effects. Dawson et al. found that their study participants required considerably more time to develop treatment goals than the time frame outlined by Polatajko and Mandich (2004) in the CO-OP treatment protocol. Two to three treatment sessions were required for Dawson et al.'s participants to develop their treatment goals, while the treatment protocol calls for one session. The authors were not able to determine why the treatment effect on untrained goals was not as positive as the treatment effect on trained goals. Dawson et al. postulated that this limitation may be due to chance or may be related to the length of the intervention. The authors questioned if a longer intervention period may have improved the treatment effect on untrained goals, since one study participant had stated that allowing more time for addressing goal transfer issues would have been helpful. Another possibility Dawson et al. put forward for the reason for the limited treatment effect on untrained goals was the difficulty that participants had in identifying their treatment goals. Although treatment effects were mostly positive and were maintained after a 3-

month follow-up period, the small number of participants in the study and lack of a control group prevents the study results from being generalizable to all adults with impaired executive functions.

2.2.2.2 Skidmore et al., 2011

In 2011, Skidmore, Holm, Whyte, Dew, Dawson, & Becker published a single-case pilot study to test the applicability of the CO-OP for an adult with cognitive impairments seven days following an acute right hemisphere stroke in an in-patient rehabilitation setting. The CO-OP treatment protocol was provided for 45 minutes per day, five days per week over the participant's two-week in-patient rehabilitation stay. The study results found that the participant's performance on self-identified goals improved to criterion on 8 of 8 trained goals; the participant, spouse, and inpatient rehabilitation team all reported satisfaction with the strategy. Although the participant's engagement in the rehabilitation process and his independence in activities of daily living improved while he was participating in the CO-OP, it is not known if the CO-OP caused these changes because of the confounding variables of the inpatient rehabilitation process itself and the spontaneous nature of some degree of recovery in the acute post-stroke period. Because of the single participant sample size, the study results are not generalizable to the acute stroke population. Because there was no follow-up, long-term effects of treatment are not known.

2.2.2.3 Dawson et al., 2013

Dawson, Binns, Hunt, Lemsky, and Polatajko (2013) published a partially randomized controlled trial on the applicability of the CO-OP on community-dwelling adults with chronic traumatic brain injury (TBI). Thirteen participants were recruited through local brain injury

associations and through advertisements on those associations' websites. Potential participants were required to be at least one year post-TBI, at least 18 years old, have no history of any other significant neurological or psychological diagnosis, have evidence of executive dysfunction, speak and understand English, and to be able to identify specific day-to-day functional difficulties that they wished to address. The first six participants were randomly allocated to either the treatment group or the control group. The other seven participants were selectively allocated to either group in order to minimize group differences in age, gender, education level, and injury severity. The average time post-TBI was 9.8 years in the experimental group and 10.8 years in the control group. Twelve participants were able to identify five or six occupational performance goals, but one participant was only able to identify two goals. In the experimental group, participants self-selected three goals for training. The other goals were not trained or discussed during the intervention. Participants in the treatment group completed twenty hours of CO-OP training, consisting of two one-hour sessions per week for ten weeks in the participants' homes or in other community environments that were relevant to their specific treatment goals. The primary outcome measure was the Canadian Occupational Performance Measure (COPM), which is used for participants to identify meaningful everyday tasks that they need to, want to, or are expected to perform but are having difficulty with. The COPM is then used by participants to rate their own performance and satisfaction with the occupational performance goals they identified. Secondary measures used in the study were the Mayo-Portland Adaptability Inventory-4 Participation Index or "M2PI" (a measure of change in participation in everyday life), the Dysexecutive Questionnaire (a measure of change in the effect of executive function on everyday activities), and the Assessment of Motor and Process Skills (a measure of change in performance). All participants had positive feelings about the treatment intervention, although

one participant found the treatment schedule too rigid. Outcome measures were administered at baseline and following the ten weeks of treatment. Within the experimental group, differences that approached significance were found on COPM performance and satisfaction scores on trained goals following treatment. Significant improvements were found on COPM performance and satisfaction scores on untrained goals as well as on M2PI scores in the experimental group compared to the control group. Study results found that the CO-OP can improve performance on trained self-selected occupational performance goals and that strategies learned during training can be successfully transferred to improve performance on untrained goals. The study authors felt that adherence to the 20 hours of training was cultivated by providing the treatment intervention in participants' homes, which helped to make the treatment program convenient and contextually relevant for participants. Although results from this study are promising, since the sample size was small, results of this study are not generalizable to the larger population of individuals with chronic traumatic brain injury. The study authors hypothesized that the lack of any treatment for the control group may also affect results, since participants in the control group may have experienced anxiety at not receiving treatment, although they had set occupational performance goals, and that this anxiety may have negatively affected their post-intervention scores. Another possible outcome that the authors postulated was that the act of setting goals may have motivated participants in the control group to begin working on these goals on their own, which may have reduced the measurable differences between the two groups. Long-term follow-up was not done, therefore long-term effects of treatment are not known.

2.2.2.4 Ng et al., 2013

Ng, Polatajko, Marziali, Hunt, & Dawson (2013) completed a pilot series of three case studies examining the feasibility of providing the CO-OP to individuals with chronic brain injury via a telerehabilitation format to provide treatment at a distance using telecommunication. Participants were recruited through advertisements on local and national brain injury association websites and newsletter as well as through word-of-mouth. Potential participants needed to be over 18 years old, at least one-year post-TBI, have impairments in executive functions, have no history of other neurological or psychiatric illness that had required hospitalization, no concurrent depression, and no substance abuse. Participants also needed to have access to a computer with a high-speed internet connection and be able to self-identify specific difficulties they were having with day-to-day functional tasks. Three male participants, all more than 10 years post-TBI, and their significant others were recruited. CO-OP sessions were provided through videoconferencing using Skype™. Participants received 20 one-hour treatment sessions provided twice weekly over 10 weeks. Each participant self-identified 5-7 goals, and chose three goals to work on during CO-OP training sessions. The remaining goals were not discussed during treatment. Following treatment, all participants and their significant others indicated improvement in both trained and untrained goals, and some improvement was maintained at three-month follow-up. The telerehabilitation format was found to be feasible to adhere to the CO-OP protocol, was acceptable by the treatment participants, and was sufficient to provide training in most treatment sessions. All participants trended toward fewer symptoms of executive dysfunction in everyday life post-treatment and at three-month follow-up. Maintenance of CO-OP treatment effects over the long-term is encouraging, although results from this study cannot be generalized due to its small sample size.

2.2.2.5 Poulin et al., 2016

In early 2016, Poulin, Korner-Bitensky, Bherer, Lussier, & Dawson published a partially randomized single blind controlled trial examining the feasibility and efficacy of the CO-OP and a computer-based training program on community dwelling adults post-stroke. Participants were recruited from a multi-site acute care hospital and six rehabilitation centres and most participants were still involved with rehabilitation programs during the study period. Potential participants were required to have had their first or recurrent stroke within the previous twelve months, demonstrate impaired executive functions on one or more neuropsychological tests [a score equal to or greater than 1.5 standard deviations below the norm on the Trails Making Test – Part B, Delis-Kaplan Executive Function System (D-KEFS) Colour-Word Interference test, or the Digit Span from the WAIS-IV], demonstrate clinical evidence of impaired executive functions as determined by clinician referrals and health record review, have MMSE scores equal to or greater than 22/30, live independently in their own home, speak English or French fluently, and be able to identify some difficulties with day-to-day activities on which treatment goals could be made. Potential participants were excluded if they had a history of severe psychiatric problems, if they had severe visual impairments that would not allow them to use a computer or read even with corrective lenses, severe post-stroke language problems as indicated by a score of less than 4 on the communication items of the Functional Independence Measure, and if they had other disabling neurological conditions such as Alzheimer's disease or multiple sclerosis. Participants were also asked to identify a significant other who would participate in interviews pre-intervention, post-intervention, and at one month follow-up to rate their perception of participants' performance in day-to-day activities that the participants wanted to improve. Each significant other was required to be an adult who was a close friend or family member who spent

time with the participant at least once per week and was fluent in either English or French. Post-stroke participants were not required to have a significant other included in the study in order to meet inclusion criteria. Twelve participants were recruited, but one dropped out during baseline assessment. Of the eleven remaining participants, two were assigned to a CO-OP treatment group because of medical conditions and practical constraints that prevented their participation in the computer training treatment group. The other nine participants were randomly assigned to either the CO-OP treatment group or the computer training treatment group. The evaluator was blind as to the treatment group each participant was placed in. All assessments and treatment interventions were completed at the participants' homes. Treatment sessions were 60 minutes in length and took place twice weekly over eight weeks for both groups. Each participant in both groups was guided to identify a minimum of five goals for day-to-day activities that he or she wanted to improve upon using the Canadian Occupational Performance Measure (COPM). Participants in the CO-OP group were asked to identify their most important goal from the COPM. Two other goals were randomly chosen from participants' COPM goals for a total of three goals to be trained during CO-OP treatment. These three goals were then the focus of intervention sessions for the participants in the CO-OP treatment group. Participants in the computer training treatment group were provided with a computer-based executive function training program involving simulations of everyday tasks (such as driving) that challenged working memory, cognitive flexibility, divided attention, inhibition, and dual-task training. Each participant completed the COPM at baseline, post-intervention, and at one-month follow-up to measure their self-perceived performance and satisfaction with their performance in each of their five goals for improvement in day-to-day activities. Participants' significant others also completed the COPM at baseline, post-intervention, and at one month follow-up to provide their

own perspectives of participants' performance on their goals. Measures of executive function (Trails Making Test B, D-KEFS Colour-Word Interference test, and WAIS-IV Digit Span), a measure of social participation (Assessment of Life Habits), and a measure of self-efficacy for performing everyday activities (The Self-Efficacy Scale for Performing Life Activities Post-stroke) were also completed at baseline, post-intervention, and at one month follow-up. Both groups demonstrated clinically and statistically significant improvements in COPM scores that were maintained one month following treatment; these improvements were corroborated by the participants' significant others. Of note, COPM scores improved for untrained goals in both groups. The study authors postulate that improvements in untrained goals for both groups may have occurred due to learning effects from treatment and generalization and transfer of these effects in both groups to other aspects of day-to-day life. The authors hypothesize that the improvement in untrained goals in the CO-OP treatment group may be directly associated with problem-solving strategies the participants learned during treatment that they then applied to other problems, while the improvement in untrained goals in the computer training treatment group may be associated with improvements in cognitive flexibility, working memory, and other executive functions that were focused on during computer training, and participants were then able to draw upon those improved skills to solve problems in day-to-day life. Both groups showed improvement in executive functions: the CO-OP treatment group improved on all three executive function measures, with the largest improvement on the Trails Making Test B; the computer training treatment group improved on only the Colour-Word Interference test and the Digit Span. The study authors hypothesize that the difference between groups on the Trails Making Test - Part B may be due to a ceiling effect in the computer training treatment group, since two participants in the computer training treatment group attained scores within normal

range on the Trails Making Test – Part B at baseline. Participants in the CO-OP treatment group showed greater improvements in self-efficacy than the computer training treatment group; study authors attribute the between-group difference in improvements in self-efficacy to the guided discovery approach utilized in the CO-OP treatment group, in which the treating clinician guided participants to discover strategies to solve their own problems. This study is unique in examinations of the efficacy of the CO-OP to improve cognition in that in addition to examining the effects of a “top down” treatment approach that focuses directly on improving performance in day-to-day activities (the CO-OP), it also examined the effects of a “bottom up” treatment approach that focuses on improving underlying cognitive skills (computer training); both approaches were found to be beneficial for participants’ performance of day-to-day activities and executive functions and benefits are maintained over time. Findings suggest that the CO-OP is particularly beneficial to improve self-efficacy. The ecological validity of study findings are strengthened by the fact that both treatment programs were provided in participants’ homes and both involved real-word activities (the CO-OP) or simulations of real-word activities (computer training). Generalizability of study results is limited by its small sample size, its lack of a control group, and the non-randomization of two study participants in their group allocation. Study results must also be interpreted with caution since most participants were also receiving other forms of rehabilitation concurrently during the study, and also since participants were all less than a year post-stroke and therefore some improvements observed during the study period may have been attributable to spontaneous recovery.

2.2.3 Summary

No best practice guidelines are yet available for the use of the CO-OP with adults with executive dysfunction. A large study has been run by Dawson and colleagues to create a treatment fidelity checklist for use of the CO-OP with this population but has not yet been published. Results of this study are being used to develop practice guidelines and training materials for clinicians to adapt the CO-OP for use with adults with executive dysfunction. These materials will not be ready for public release until at least June 2016 (D. Dawson, personal communication, October 28, 2015).

Although the studies published to date of the effect of the CO-OP on adults with executive dysfunction have had promising findings, these results should be interpreted with caution due to small sample sizes in all five studies and lack of a control group in four of the five studies. The study results cannot be generalized to either the chronic brain injury population, the acute stroke population, or the sub-acute stroke population that was studied, nor can it be assumed that the study results are replicable in the Parkinson's population; however, these exploratory investigations of the effects of the CO-OP with adults with cognitive impairment offer preliminary findings which further investigations can build upon. Although the results of the large study recently completed (but not yet published) by Dawson and colleagues are intended to provide practice guidelines for the adult population with executive dysfunction, no studies on the effects of the CO-OP with adults with Parkinson's disease-related cognitive impairment have been published or are known to be currently underway.

2.3 Purpose of the Study

Cognitive impairment is experienced to varying degrees by more than 50% of people diagnosed with Parkinson's disease (Moberg, 2007). Cognitive impairment in Parkinson's disease has a distinct pattern, with typical impairments experienced in attention (sustained, selective, divided, and alternating), information processing speed, memory recall, visuospatial skills, psychomotor functions, and executive functions (Botha & Carr, 2012; Emre, Aarsland, & Brown, 2007; Mohlman, Chazin, & Georgescu, 2011; Park & Stacy, 2009; York & Alvarez, 2008). Impairments in these cognitive domains are known to negatively affect health-related quality of life for people with Parkinson's disease and their caregivers, even for individuals with mild cognitive impairment (McKinlay, Grace, Dalrymple-Alford, Anderson, Fink, & Roger, 2010; Paris, et al., 2011; Sammer, Reuter, Hullman, Kaps, & Vaitl, 2006; Sinforiani, Banchieri, Zucchella, Pacchetti, & Sandrini, 2004). Impairments in executive functions in particular for individuals with Parkinson's disease can limit participation in desired occupations such as socialization, instrumental activities of daily living, productive work, and leisure activities, even if motor symptoms are well-controlled by medications (Foster & Hershey, 2011), and thus can also impact negatively on patient-perceived health-related quality of life (Eriksson, Kottorp, Borg, & Tham, 2009).

Cognitive deterioration in Parkinson's disease has been correlated with increased caregiver stress (McKinlay, Grace, Daylrymple-Alford, Anderson, Fink, & Roger, 2008) and earlier placement in long-term care (Aarsland, Larsen, Tandberg, & Laake, 2000; McKinlay, Grace, Dalrymple-Alford, & Roger, 2010). Although it can be intrinsically rewarding for many reasons, caregiving for family members with deteriorating cognition is often a bigger strain on

caregivers' time, energy, and finances than general caregiving (Baker & Robertson, 2008), and typically stretches over many years (Coon et al., 2003; Romero-Moreno et al., 2011; Yap et al., 2005). Chronic stresses associated with the burden of caring for family members with Parkinson's disease have been found to increase caregiver depression, negatively affect caregivers' social lives, and to negatively affect their quality of life (Martinez-Martin, et al., 2005; Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006). Caregiver burden is higher for live-in caregivers than non-live-in caregivers, and spouses are reported to be the most stressed of all caregivers (Raccichin, Castellani, Civerchia, Fioravanti, & Scarpino, 2009).

The purpose of this study was to determine the applicability of the Cognitive Orientation to daily Occupational Performance (CO-OP) as a meta-cognitive rehabilitation strategy for individuals with Parkinson's disease-related cognitive impairment.

2.4 Objectives of the Study

To determine:

1. The efficacy of the CO-OP protocol on trained tasks of basic and instrumental activities of daily living with individuals with Parkinson's-related cognitive impairment.
2. If the strategies taught by the CO-OP protocol are generalizable by participants to the same trained tasks when the tasks are completed outside of treatment sessions.
3. If the strategies taught by the CO-OP protocol are transferable by participants to other tasks that are not trained in treatment sessions.
4. If results of the CO-OP protocol are maintained after 3-month follow-up.

5. The effect of the CO-OP training protocol on:
 - a.) Participants' perceived performance on, and satisfaction with, self-care, productivity, and leisure occupations
 - b.) Participants' self-rated health-related quality of life
 - c.) Caregiver stress for live-in caregivers / significant others
 - d.) Participants' perception of their own cognitive abilities

2.5 Hypotheses

H₁ – There will be an effect or multiple effects of the CO-OP on individuals with Parkinson's-related cognitive impairment, as measured with the COPM, and the PDQ-39.

H₂- There will be an effect or multiple effects of the CO-OP on the caregivers / significant others of individuals with Parkinson's-related cognitive impairment as measured with the Zarit Burden Interview.

3.0 METHODOLOGY

3.1 Research Design

The research design used a concurrent mixed methods procedure (Creswell, 2009), combining experimental-type quantitative and naturalistic qualitative elements (DePoy & Gitlin, 2005; Stake, 2005) in an interrupted time-series A-B-A single-subject design (DePoy & Gitlin, 2005; Portney & Watkins, 2009). As a single subject design, quantitative and qualitative data collection methods were used and were combined together to examine each case on its own and to examine all three cases as a group. Data was triangulated by comparing quantitative and qualitative data to each other. Descriptions from qualitative data explained and corroborated quantitative data, allowing the complexity of the cases to be examined as thoroughly as possible to provide maximal information (DePoy & Gitlin, 2005).

3.1.1 Quantitative Methodology: Single Subject Design

A single-subject design with multiple baselines allows for multiple measures of a single person rather than a single measurement of many subjects. Internal validity can be maintained in a single-subject design by withdrawing and reinstating phases to replicate intervention effects (Portney & Watkins, 2009); this process is known as an interrupted time series (McDowall, 2004; Portney & Watkins, 2009). When the number of participants is small, this design is more rigorous than an experimental control group design (M. Law, personal communication, October 29, 2012). Repeated measures of an A-B-A design document natural fluctuations in dependent variables during observation phases of no treatment (“A” phases). In effect, each single subject acts as their own control. These repeated measures also provide information about the trend and variability of responses to the intervention during the “B” phase (Fetters & Tilson, 2012; Portney & Watkins, 2009).

Single-subject methodology allows for intimate examination of the relationship between the intervention and any number of dependent variables particular to the study participant's own environmental context, some of which may not have been anticipated prior to implementing the study and may have been missed if a more prescriptive randomized control group methodology were used (DePoy & Gitlin, 2005; Stake, 2005). The repeated measurements characteristic of a time-series single-subject design allow for investigation of data trends and patterns and their variability over time, another advantage which is not possible in a group study (Portney & Watkins, 2009). Single-subject methodology is ideal to provide additional empirical data on the long-term effects of the CO-OP treatment protocol because a single-subject methodology is sensitive enough to measure even subtle changes in an individual case over time, whereas such changes may be missed when examining a group (DePoy & Gitlin, 2005; Stake, 2005).

As there is still very little known about the effects of cognitive rehabilitation on individuals with Parkinson's disease and cognitive impairment, and as the CO-OP has not yet been utilized in the Parkinson's population, this study is largely exploratory in nature, and no theories yet exist to be tested. A single-subject design is an appropriate design to generate theories surrounding the research question that may be tested in future, larger experimental studies (Biglan, Ary, & Wagenaar, 2000; DePoy & Gitlin, 2005).

3.1.2 Qualitative Methodology

Qualitative research is often one of the first steps for investigating a particular phenomenon in which little research work has been done before (Luborsky & Lysack, 2006). Since the available literature on the effects of cognitive rehabilitation on individuals with Parkinson's disease-related cognitive impairment is sparse, and since no literature yet exists at all

on the effects of the CO-OP treatment program for this population, inclusion of qualitative research methodology was appropriate in this study. Qualitative methodology aims to develop new knowledge with “naturalistic discovery, identification, and description of basic features of the worlds people live in and their experiences of those worlds,” (Luborsky & Lysack, 2006, p. 326-327). Naturalistic qualitative measures can capture a “thick description” (Stake, 2005, p. 45) of particular phenomena, experiences, processes, meanings, and salience that often cannot be adequately measured by pre-determined data collection methods (Luborsky & Lysack, 2006; Stake, 2005). The use of a qualitative research method in this exploratory study of the effect of the CO-OP on individuals with Parkinson’s disease-related cognitive impairment facilitated exploration of the multiple perspectives of participants’ and caregivers’ views, beliefs, and values that reflected features of their everyday lived experiences that were related to the research question (Luborsky & Lysack, 2006) and provided data that is richer in detail than could be gathered by quantitative research methods alone (Luborsky & Lysack, 2006).

3.2 Participants

3.2.1 Preamble

After the study protocol and recruitment materials were approved by the University of Manitoba Research Ethics Board and informed consent was obtained from all participants and their caregivers / significant others, three participants with Parkinson’s disease and one caregiver / significant other for each participant with Parkinson’s disease were recruited. For brevity, study participants with Parkinson’s disease will most often be referred to simply as “participants” throughout the remainder of this thesis, while study participants who are caregivers / significant others will most often be referred to simply as “caregivers.”

3.2.2 Inclusion Criteria for Participants with Parkinson's Disease

Inclusion criteria were: individuals with a diagnosis of Idiopathic Parkinson's Disease confirmed by a movement disorder neurologist; the presence of a live-in caregiver or significant other who was also willing to participate in the study; individuals with mild cognitive impairment (MCI) as detected by scores falling above 16/30 and below 26/30 on the Montreal Cognitive Assessment (MoCA) (Hoops, et al., 2009); individuals with Schwab and England ADL Scale scores between 60% and 90% (to include individuals physically and cognitively able to participate in and benefit from the study); individuals with Hoehn and Yahr Scale scores between Stage 1 and Stage 3 (to include individuals physically able to participate in and benefit from the intervention). Selected individuals also needed to self-report some degree of difficulty (any range, from mild to severe) completing routine functional activities that they felt may be related to cognitive changes that were new since their PD diagnosis.

3.2.3 Exclusion Criteria for Participants with Parkinson's Disease

Exclusion criteria were: individuals with a diagnosis of atypical parkinsonism, i.e., Progressive Supranuclear Palsy, Multiple System Atrophy, Cortico-basal Ganglionic Degeneration, Lewy-Body Dementia, drug-induced parkinsonism (because of differences in disease processes, prognoses, and response to anti-Parkinson's medications); individuals with young-onset Idiopathic Parkinson's Disease (because of differences in disease process, prognosis and response to anti-Parkinson's medications); co-morbidities associated with cognitive impairment, i.e., Alzheimer's disease, traumatic brain injury, vascular dementia, cerebral vascular accident, congenital mental retardation, multiple sclerosis, Korsakoff's syndrome, etc. (due to confounding dependent variables); individuals with depression not well-controlled with medication (due to confounding dependent variables) as indicated by scores of 17 or higher the

Beck Depression Inventory; and individuals with Parkinson's disease dementia (PDD) as indicated by scores of 16/30 or lower on the MoCA (Hoops, et al., 2009) (to exclude individuals who may not have been cognitively able to participate in or benefit from the study). Individuals living outside the boundaries of the city of Winnipeg were also excluded because of practicality limitations for providing a community-based intervention and lack of budget for researcher travel.

3.2.4 Inclusion Criteria for Caregivers / Significant Others

Each caregiver that was included needed to live in the same residence as the corresponding study participant with Parkinson's disease, and also needed to be willing to participate in the study.

3.2.5 Exclusion Criteria for Caregivers / Significant Others

Caregivers with dementia as detected by scores falling at or below 16/30 on the MoCA (Hoops, et al., 2009) were not included, because they would not have adequate cognition to be able to participate in the study.

3.2.6 Sample Selection

Study recruitment posters (see Appendix A) were placed in locations visible to patients attending the Movement Disorder Clinic at Deer Lodge Centre. Potential study participants who happened to be visiting the Movement Disorder Clinic for reasons unrelated to the study were approached individually by a staff member of the Movement Disorder Clinic (with the exception of the principal investigator, all clinic staff members were encouraged to approach potential study participants) and were asked if they would be interested in learning about a new study trial. Potential study participants who were interested were handed an information sheet (see Appendix A) about the study. Movement Disorder Clinic patients who were on the active caseload or the

wait list for occupational therapy were not included due to the potential for conflict of interest for the principal investigator. The posters and information sheets described the purpose of the study, participant criteria, the time commitment required from potential participants and their caregivers, the voluntary nature of the study, and also disclosed that the principal investigator would be the treating clinician. The posters and information sheets directed potential participants to contact the clinical resource nurse by telephone or e-mail for more information about the study and to indicate if they were interested in participating. When contacted, the clinical resource nurse briefly explained the purpose of the study, provided the potential participant and the potential participant's caregiver with Research Participant Information and Consent forms (see Appendices B and C) and encouraged them to contact the principal investigator if they required further information about the study or if they required clarification of the Research Participant Information and Consent forms. If potential participants contacted the clinical resource nurse and indicated that they and their corresponding caregivers were still interested in participating in the study, a meeting was scheduled at the Movement Disorder Clinic in which the clinical resource nurse orally reviewed the Research Participant Information and Consent forms together with each potential participant and their corresponding caregiver. The principal investigator was available nearby to provide further study information or clarification of the forms if needed. After the forms were reviewed and all questions were answered, written consent was obtained from participants and their corresponding caregivers who agreed to be enrolled in the study. Once enrolled, participants and caregivers were reimbursed for parking costs associated with attending study sessions at the Deer Lodge Centre Movement Disorder Clinic.

3.3 Instrumentation

3.3.1 Screening Instruments

3.3.1.1 Montreal Cognitive Assessment (MoCA)

The MoCA is a standardized outcome measure designed to screen for mild cognitive impairment and takes approximately 10 minutes to administer. It assesses the following cognitive domains: attention, concentration, executive functions, memory, language, visuoconstructional skills, abstract reasoning, calculations, and orientation. A score of 26 points or above out of a possible 30 is considered normal (Nasreddine, 2005). Scores between 17 and 26 points out of 30 meet diagnostic criteria for mild cognitive impairment (MCI) in Parkinson's disease (Hoops, et al., 2009), and scores below 17 out of 30 meet diagnostic criteria for Parkinson's disease dementia (PDD) (Hoops, et al., 2009). The MoCA must be administered by a clinician with experience in administering standardized cognitive tests, such as a physician, psychologist, registered nurse, or occupational therapist. The MoCA was selected because it is considered to be a sensitive screening instrument of mild cognitive impairment and dementia in Parkinson's disease (Hoops, et al., 2009).

Although most published investigations of the effects of cognitive training on cognitive impairment in Parkinson's disease have utilized the Mini Mental Status Exam (MMSE) as a baseline descriptive measure and/or as a measure of inclusion or exclusion (Edwards et al., 2013; Mohlman, et al., 2010; Mohlman, Chazin, & Georgescu, 2011; Nombela, et al., 2011; Paris, et al., 2011; Petrelli et al., 2014; Petrelli et al., 2015; Sammer, Reuter, Hullmann, Kaps, & Vaitl, 2006; Sinforiani, Banchieri, C., Pacchetti, & Sandrini, 2004) and the MMSE is widely used clinically, the MoCA is considered superior to the MMSE for detection of cognitive impairment

in Parkinson's disease (Hoops, et al., 2009). An investigation of the validity of both measures in the detection of MCI and dementia in Parkinson's disease found that the MoCA is a more sensitive screening instrument than the MMSE, in part because of the MMSE's ceiling effect on detecting milder cognitive impairments. Therefore, the MMSE was not included as a measure in this study.

3.3.1.2 Beck Depression Inventory (BDI)

The Beck Depression Inventory (BDI) is one of the most frequently administered measure of depression in Parkinson's disease (Levin, Llabre, & Weiner, 1988). The BDI is a self-administered questionnaire with 21 groups of statements designed to measure an individual's attitudes and symptoms of depression (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961). Statements within each group are numerically ranked from 0 to 3, with higher numbers indicating worse severity of the attitude or symptom (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961). Individuals are asked to choose the statement within each group of statements that most accurately reflects how they have been feeling over the previous two weeks, including the day of completion of the questionnaire. The numerical rankings for each statement that has been chosen are added to achieve a total score. Scores from 1-10 indicate normal mood fluctuations, scores from 11-16 indicate a mild mood disturbance, scores from 17-20 indicate borderline clinical depression, scores from 21-30 indicate moderate depression, scores from 31-40 indicate severe depression, and scores over 40 indicate extreme depression (Beck, 1996). The Beck Depression Inventory has been found to have high internal consistency and inter-rater reliability as well as high factorial validity in both psychiatric populations (Beck, Steer, &

Garbin, 1988) and the Parkinson's disease population (Levin, Llabre, & Weiner, 1988; Visser, Leentjens, Marinus, Stiggelbout, & van Hilten, 2006).

3.3.1.3 Schwab and England Activities of Daily Living (ADL) Scale

The Schwab and England ADL Scale is the fifth of five parts of the Unified Parkinson's Disease Rating Scale (UPDRS) (Fahn & Elton, 1987a). The Schwab and England ADL Scale is widely used (We Move, 2013) and is designed to be used with individuals with Parkinson's disease to measure their independence level and speed with activities of daily living in a percentage form (Fahn & Elton, 1987b). It can be administered by a clinician or self-administered. Higher percentage scores indicate higher levels of independence, with individuals scoring 100% being fully independent with all activities and with normal speed and ability, and individuals scoring 0% being fully dependent for mobility and for basic body functions such as swallowing, bowel, and bladder functions (Fahn & Elton, 1987a). Individuals scoring 60% can do most activities slowly and with much effort, and are dependent for some activities (Fahn & Elton, 1987a).

3.3.1.4 Hoehn and Yahr Scale

The Hoehn and Yahr scale is a widely used (Bhidayasiri & Tarsy, 2012) global scale designed to describe the stages of progression of Parkinson's disease signs and can be scored by any professional medical clinician (Hoehn & Yahr, 1967; We Move, 2004). Scores range from "0 - No visible symptoms of Parkinson's disease" to "5 - Confinement to a bed or wheelchair unless aided," (Hoehn & Yahr, 1967).

3.3.1.5 Stroop colour-word interference test

The Stroop test is a cognitive interference task that measures selective attention, inhibition, and processing speed (Strauss, Sherman, & Spreen, 2006). There are multiple versions of the Stroop test and no one version is considered to be superior to the others (National Institute of Neurological Disorders and Stroke, 2013). It consists of three phases: in the “word” phase, the participant is presented with a written colour name that does not correspond to the actual colour of the letters. The participant is then asked to name the written colour. In the “colour” phase, the participant is presented with various coloured shapes, and then is asked to identify the colours of the shapes. Lastly, in the “colour-word” phase, the participant is presented again with a written colour name that does not correspond to the ink colour of the letters. The participant is then asked to name the colour of the printed letters (MacLeod, 1998; Stroop, 1935). The Stroop test requires approximately 2 minutes to administer each of the three phases. Each phase is scored according to how many items are answered correctly in 45 seconds, with higher scores indicating better cognitive performance. The Stroop test is considered to have high test-retest and inter-rater reliability across different versions (Chafetz & Matthews, 2004; Jensen, 1965), and also good construct validity (May & Hasher, 1998). It has been shown to be a valid predictor of change over time in the Huntington’s disease population (Stout, Paulsen, Queller, Solomon, Whitlock, Campbell, et al., 2011), but its ability to predict change over time in the Parkinson’s disease population is not known. The version of the Stroop used in the Unified Huntington’s Disease Rating Scale (Huntington Study Group, 1996) was used in this study because no one version of the Stroop is considered superior to any other, and because Huntington’s disease is also a neurodegenerative movement disorder that is known to impair cognition, including executive functions (Paulsen, 2003). In this study, the Stroop test was

included as a cognitive measure in addition to the MoCA because the MoCA does not directly measure inhibition, the latter which is one of many executive functions that can be impaired in individuals with Parkinson's disease-related cognitive impairment (York & Alvarez, 2008).

3.3.2 Quantitative Data Collection Instruments

3.3.2.1 Canadian Occupational Performance Measure (COPM)

The COPM is a semi-structured interview focusing on client-centred problem identification (Law, Baptiste, Carswell, McColl, Polatajko, & Pollock, 2005) that is founded on the Canadian guidelines for client-centred occupational therapy practice (Canadian Association of Occupational Therapists, 1997) and requires approximately 30-40 minutes to administer. The COPM consists of three sections: self-care (basic and instrumental activities of daily living); productivity (education and work); and leisure (play, leisure, and social participation). The assessment begins with self-report of occupational performance issues. The identified occupational performance issues are then rated by the client according to importance on a 10-point Likert scale. The five issues identified as most important to the client are then rated again first according to the client's self-determined performance level and second according to the client's self-determined satisfaction with their performance. Since the COPM is designed to be used as a measure of change, performance and satisfaction levels are scored again after a period of time, (usually during which an intervention has been administered). A 2-point change on any subscale within the COPM is considered to be clinically significant (Law, Baptiste, Carswell, McColl, Polatajko, & Pollock, 2005). The COPM is applicable to wide ranges of clients, settings, and disabilities (McColl & Pollock, 2005). Scores have been shown to have good reliability and validity, and are highly responsive to change (McColl & Pollock, 2005). The COPM was also selected for this study because it is an outcome measure that is built into the CO-OP treatment

protocol (Polatajko & Mandich, 2004). The COPM is integral to the CO-OP protocol because it is an excellent tool for setting goals and for measuring change (Polatajko, Green, & Bernie, 2013). In this study, the COPM was used as the primary outcome measure to detect participants' self-determined performance levels and satisfaction with their performance levels on five occupational performance issues pre-intervention, mid-intervention, immediately post-intervention, and at three month follow-up.

3.3.2.2 Parkinson's Disease Questionnaire – 39 (PDQ-39)

The Parkinson's Disease Questionnaire (PDQ-39) is the most widely used Parkinson's-specific measure of health-related quality of life (Jenkinson, Fitzpatrick, & Peto, 2013). It is a self-administered questionnaire containing thirty nine questions that cover eight aspects of health-related quality of life: mobility (10 items), activities of daily living (6 items), emotional well-being (6 items), stigma (4 items), social support (3 items), cognition (4 items), communication (3 items), and bodily discomfort (3 items). Patients are asked to select the frequency of each problem item occurring over the past month on a 5-point scale (never / occasionally / sometimes / often / always or cannot do at all). Scores for each item range from 0-4 (0 = never, 4 = always or cannot do at all). The sum of scores on each dimension is divided by four, then multiplied by the total number of questions in that dimension, then multiplied by 100. Each dimension score is described as a total out of 100, with a score of "0" equal to no difficulty at all and a score of "100" equal to the maximum level of difficulty possible. Scores can be obtained for each of the eight scales separately or the total from each scale can be added together and then divided by 8 to obtain the Summary Index score, which represents the overall subjective quality of life of the individual being tested. Lower scores indicate better subjective quality of life. The PDQ-39 was developed on the basis of interviews with people diagnosed with

Parkinson's disease (Peto, Jenkinson, Fitzpatrick, & Greenhall, 1995), and has been widely validated for test-retest, content, and construct validity, (Jenkinson, Peto, Greenhall, & Hyman, 1997; Jenkinson, Fitzpatrick, & Peto, 2013; Peto, Jenkinson, Fitzpatrick, & Greenhall, 1995). The PDQ-39 requires approximately 10-20 minutes to administer, depending on whether the individual being tested has mild, moderate, or advanced Parkinson's disease, with increasing time required for individuals with more advanced disease (Kim, Dahlberg, & Hagell, 2006). A six point change on the total score from 0 to 100 is considered to be clinically significant (Fitzpatrick, Norquist, & Jenkinson, 2004).

3.3.2.3 Zarit Burden Interview (ZBI)

The Zarit Burden Interview (ZBI) is the most widely used measure of caregiver burden (Bachner & O'Rourke, 2007; O'Rourke & Tuokko, 2003). It is a self-administered 22-item questionnaire designed to assess caregivers' perceptions of burden related to caring for an older person with dementia or a person with a disability (Mapi Research Trust, 2013; Zarit, Reever, & Bach-Peterson, 1980). Questions on the interview address caregivers' physical health, as well as emotional, social, and financial wellbeing (Rehabilitation Institute of Chicago, 2013). The ZBI takes approximately 5-10 minutes to administer. Caregivers are asked to select the frequency of each problem item on a 5-point scale (never / rarely / sometimes / quite frequently / nearly always). Scores for each item range from 0-4 (0 = never, nearly always = 4). Scores range from 0 to a maximum of 88 points. ZBI scores of 24 or higher identify caregivers that are highly burdened and require further assessment (Rehabilitation Institute of Chicago, 2013; Schreiner, Morimoto, Arai, & Zarit, 2006). Originally developed for use with caregivers of community-dwelling older adults with Alzheimer's disease, the ZBI has been tested and used to measure change over time in many other populations, including Parkinson's disease (Bachner &

O'Rourke, 2007; Carod-Artala, Mesquitab, Ziomkowskic, & Martinez-Martin, 2013; Leroi, McDonald, Pantula, & Harbishettar, 2012; Soulas, Sultan, Gurruchaga, Palfi, & G., 2012). Short versions of the scale exist, however the 22-item version is recommended for research and clinical practice whenever feasible (Bachner & O'Rourke, 2007).

3.3.3 Qualitative Data Collection

3.3.2.1 Direct Observation Record

Throughout the entire study period from the beginning of the baseline pre-intervention phase to the end of the 3 month follow-up, field notes consisting of direct observations of the behaviours of study participants and their caregivers / significant others and relevant contextual events and environmental features were recorded with detailed descriptions in a log document. As prescribed by Lysack, Luborsky, & Dillaway, the observation record consists of “detailed nonjudgmental, concrete descriptions of what has been observed,” (2006, p. 342). It is important to remember that, without comparison to other data sources, the meaning of observations from the direct observation record can only be inferred (Lysack, Luborsky, & Dillaway, 2006). Observational data collected during the study provided rich, detailed information related to interactions between study participants and the physical and social environments in which the participants worked toward their CO-OP treatment goals (Lysack, Luborsky, & Dillaway, 2006), as well as detailed information related to the participants' performance on self-selected CO-OP treatment goals. Examples of observations that were recorded include non-verbal body language, facial expression, and tone of voice of participants and caregivers, as well as detailed descriptions of physical environmental aspects that were relevant to the context of the study session. Although observations of the behaviours of study participants and their caregivers

included non-verbal behaviours such as facial expressions and tones of voice, the principal investigator took care to remain aware of the strong influence of Parkinson's disease symptoms on facial expressions and tones of voice in the form of masked facies and hypophonia, both of which can significantly reduce the range of facial and vocal expression of individuals with Parkinson's disease (Bowers, et al., 2006; Liotti, et al., 2003).

3.3.2.2 In-Depth Interviews

A semi-structured interview format was used in order to obtain the most detailed information possible from the perspective of the participants and their caregivers (Lysack, Luborsky, & Dillaway, 2006). The interviews resembled guided conversations using an interview guide consisting of open-ended questions. When appropriate, the interviewer asked value neutral probing follow-up questions in order to elicit more information from the interviewee (Lysack, Luborsky, & Dillaway, 2006). Appropriate situations in which probing follow-up questions were asked included when examples, explanations, and rationales for interviewees' responses were necessary to capture the participants' beliefs and views as thoroughly and accurately as possible (Lysack, Luborsky, & Dillaway, 2006). Participant and caregiver responses to interview questions were recorded in short hand in a log book. Observations regarding body language and affect were also recorded in a log book. Interviews were audio recorded using two digital recorders (in case of failure of one recorder) in order to provide as much data as possible for analysis, including a verbatim record, and to verify the accuracy of the data collected (Lysack, Luborsky, & Dillaway, 2006). Please see Appendices D-I for interview guides.

3.3.2.3 Reflective Journal Log

Stake (2005) stresses that, when completing qualitative single-subject research in particular, the most critical rule is to observe reflectively. When assuming a reflective viewpoint, the researcher is able to delve deeper into cross-interpretation of meaning in impressions, recollections, and records in order to relate them to contexts and experience (Stake, 2005). A reflective journal log was maintained for all treatment and data collection sessions as a deliberate, systematic self-examination process for the principal investigator. The principal investigator's thoughts, feelings, and reactions related to questions, quandaries, and complexities that arose as the study progressed were recorded. Data from researcher self-examination are important on their own merits (Lysack, Luborsky, & Dillaway, 2006), but an awareness of this data is also important because of its potential to bias the processes of data collection and analysis, which may also influence study results (Lysack, Luborsky, & Dillaway, 2006). Researcher bias cannot be eliminated (Lysack, Luborsky, & Dillaway, 2006; Thorne, Reimer Kirkham, & MacDonald-Emes, 1997), therefore it is important to identify and account for its influence on emerging interpretations as much as possible (Lysack, Luborsky, & Dillaway, 2006; Thorne, Reimer Kirkham, & MacDonald-Emes, 1997).

3.4 Procedure

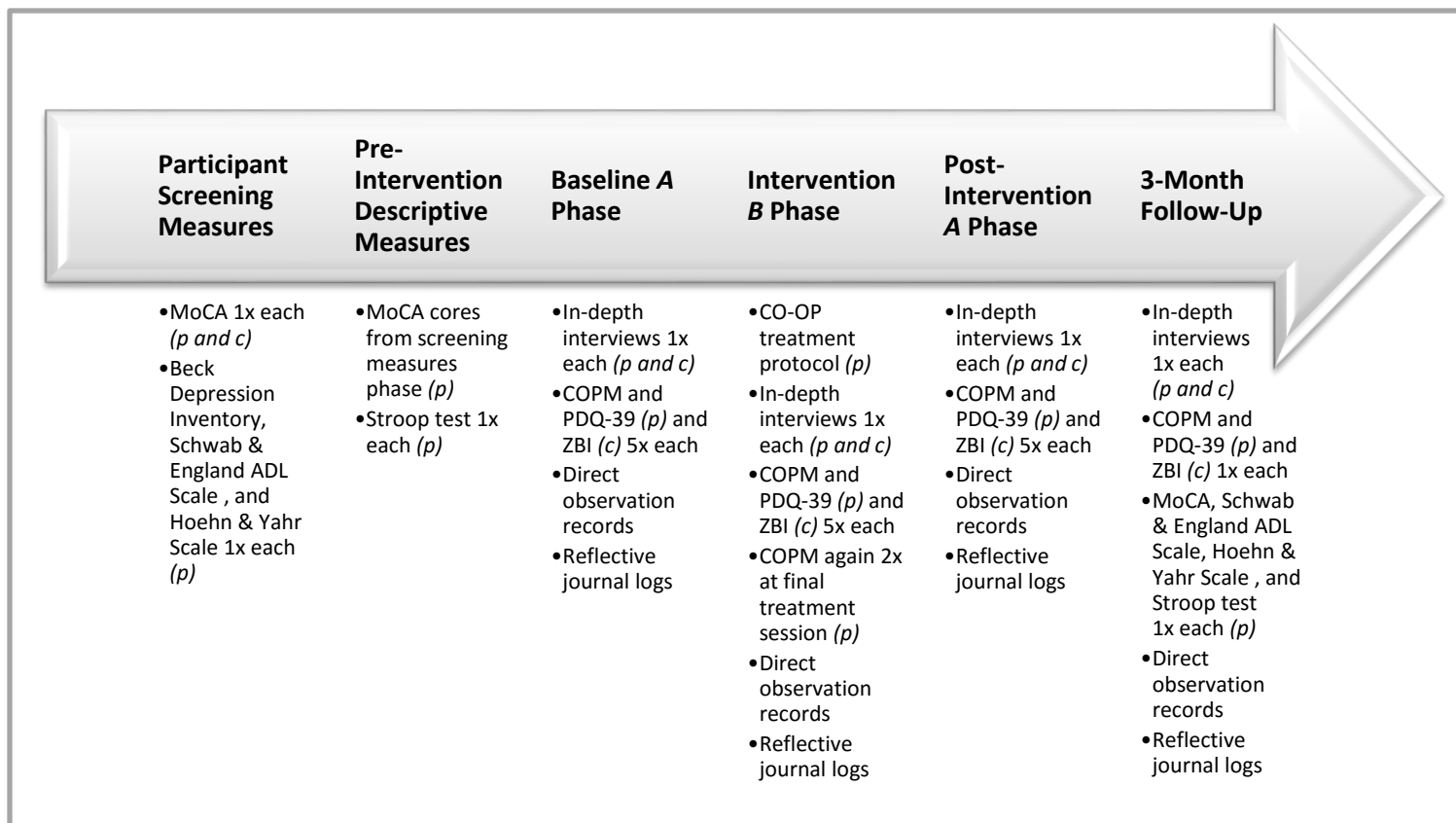
3.4.1 Study Timeline

All study participants and caregivers needed to commit to a total of 5.5 months to be involved in the study. Study involvement was most intense during the first 10 weeks, which consisted of the following: 1) pre-intervention *A* phase over two weeks; 2) intervention *B* phase over 6 weeks; and 3) post-intervention *A* phase over two weeks. Participants and caregivers were

given a break from direct study involvement for the next three months, following which they completed 4) a one-time follow-up on a single day.

Final approval of the study protocol and addendums was granted by the University of Manitoba Research Ethics Board in February, 2014, approval from the research ethics board at Deer Lodge Centre was granted later the same month. The study was also registered on the ClinicalTrials.gov online clinical study database service of the U.S. National Institutes of Health under the ClinicalTrials.gov identifier number NCT02007785. Participant recruitment began in late February 2014 and continued until 3 participant and caregiver pairs were recruited. The final participant/caregiver dyad was recruited in May 2014. Participants and caregivers began the pre-intervention *A* phase as soon as possible after recruitment, therefore the participation of each participant/caregiver dyad was staggered. The first participant/caregiver dyad began participation in the study in March 2014, and participated in the *A-B-A* phases over 8 weeks, ending in May 2014. The 3-month follow-up for this dyad took place in August 2014. The second participant/caregiver dyad began participating in the study in April, and participated in the *A-B-A* phases over 8 weeks which ended in June. The 3-month follow-up for this dyad took place in September. The third participant/caregiver dyad began participating in the study in May, also participated in the *A-B-A* phases over 8 weeks, ending in July. The 3-month follow-up for this dyad took place in October 2014. Figure 1 on the following page outlines the study protocol timeline and lists which measures were used at screening, as descriptive measures, and at each of the four study phases.

Figure 1 Study Protocol



p = participant; *c*= caregiver

The following table summarizes the purpose of each measure used in the study, as well as when and with whom each measure was used.

Table 3.1 Quantitative and Qualitative Measures

Measure	Purpose	When Used	With Whom
Montreal Cognitive Assessment (MoCA) (Nasreddine, 2005)	<ul style="list-style-type: none"> • Screening of participants and caregivers • Descriptor of participants' cognitive status pre- and post-intervention 	<ul style="list-style-type: none"> • Participant and caregiver recruitment screening • 3-month follow-up 	<ul style="list-style-type: none"> • Potential study participants and their caregivers • Participants enrolled in the study
Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961)	Screening of participants	Participant screening	Potential study participants
Schwab and England Activities of Daily Living (ADL) Scale (Fahn & Elton, 1987)	<ul style="list-style-type: none"> • Screening of participants • Descriptor of participants' independence level pre- and post-intervention 	<ul style="list-style-type: none"> • Participant screening • 3-month follow-up 	<ul style="list-style-type: none"> • Potential study participants • Participants enrolled in the study
Hoehn and Yahr Scale (Hoehn & Yahr, 1967)	<ul style="list-style-type: none"> • Screening of participants • Descriptor of participants' PD stage pre- and post-intervention 	<ul style="list-style-type: none"> • Participant screening • 3-month follow-up 	<ul style="list-style-type: none"> • Potential study participants • Participants enrolled in the study
Stroop Test (Huntington Study Group, 1996)	Descriptor of baseline and post-intervention cognitive status	<ul style="list-style-type: none"> • Prior to beginning the baseline A phase • 3-month follow-up 	Participants
Parkinson's Disease Questionnaire – 39 (PDQ-39) (Peto, Jenkinson, Fitzpatrick, & Greenhall, 1995)	<ul style="list-style-type: none"> • Measure of change • Descriptor of health-related quality of life 	<ul style="list-style-type: none"> • Baseline pre-intervention phase • Intervention phase • Post-intervention phase • Three months post-intervention 	Participants
Zarit Burden Interview (Zarit, Bach-Peterson, 1980)	<ul style="list-style-type: none"> • Measure of change • Descriptor of caregiver burden 	<ul style="list-style-type: none"> • Baseline pre-intervention phase • Intervention phase • Post-intervention phase • Three months post-intervention 	Caregivers
Canadian Occupational Performance Measure (COPM) (Law, Baptiste, Carswell, McColl, Polatajko, & Pollock, 2005)	<ul style="list-style-type: none"> • Measure of change • Descriptor of importance, performance, and satisfaction with self-selected task-oriented goals • Goal-setting tool for treatment 	<ul style="list-style-type: none"> • Baseline pre-intervention phase • Start of intervention • Post-intervention phase • Three months post-intervention 	Participants
In-Depth Interviews	<ul style="list-style-type: none"> • Detailed descriptors of phenomena that may not be captured by quantitative measures 	<ul style="list-style-type: none"> • Baseline pre-intervention phase • Intervention phase • Post-intervention phase • Three months post-intervention 	Participants and caregivers
Direct Observation Record	<ul style="list-style-type: none"> • Detailed descriptor of phenomena that may not be captured by quantitative measures 	<ul style="list-style-type: none"> • During each data collection session throughout the study period 	Participants and caregivers

Measure	Purpose	When Used	With Whom
Reflective Journal Log	<ul style="list-style-type: none"> • To reflectively examine the thoughts, feelings, and reactions of the researcher • Descriptor of phenomena that may not be captured by quantitative measures 	<ul style="list-style-type: none"> • Following each data collection session throughout the study period 	Done by the principal investigator alone, without direct involvement with participants or caregivers

3.4.2 Screening Measures

The MoCA, the Beck Depression Inventory, the Schwab and England ADL Scale, and the Hoehn and Yahr Scale were all utilized with each potential participant as part of the selection criteria after potential participants and their corresponding caregivers had provided written consent. Potential participants with scores that fell within the ranges specified in the inclusion criteria (section 3.2.2) for each of the three measures were considered for enrollment in the study.

3.4.3 Pre-Intervention Descriptive Measures

In addition to being used as part of the participant selection criteria, the MoCA score obtained during participant selection was also used as a descriptor to ascertain the baseline cognitive status of each participant. The MoCA was also completed with each participant's caregiver to determine the caregiver's cognitive status; this was done because same-age caregivers of individuals with Parkinson's disease are likely to be older adults, and are therefore more likely to be experiencing cognitive impairment themselves (Glisky, 2007), which has the potential to affect the reliability of caregiver responses on other data collection tools. The Stroop test was completed with each participant pre-intervention to ascertain cognitive status of participants in regard to attention, inhibition, and processing speed. It was not hypothesized that the study intervention would have an effect on performance on tests of cognitive status (Dawson, Gaya, Hunt, Levine, Lemsy, & Polatajko, 2009); however, because mild cognitive impairment

in Parkinson's disease often deteriorates into dementia as the disease progresses (Broeders, de Bie, Velseboer, Speelman, Muslimovic, & Schmand, 2013), the MoCA and the Stroop test were completed once again at the 3-month follow-up to ensure no rapid deterioration in participant cognition had occurred during the study period, which could confound data results.

3.4.4 Baseline A Phase

At the start of the baseline A phase, in-depth semi-structured interview sessions were administered by the principal investigator one-on-one with each participant and their caregiver separately. All interview sessions with participants were held in the Movement Disorder Clinic occupational therapy treatment room at Deer Lodge Centre, while all interview sessions with caregivers were held in the Occupational Therapy ADL Suite a short distance down the hall at Deer Lodge Centre. All interview sessions were audio recorded using two digital recorders (two recorders were used in case of failure of one recording device). The caregivers completed their interviews as the first part of data collection during this phase, while the participants completed their interviews as the second part collection during this phase (immediately following the participants' first completion of the PDQ-39 and the COPM, described in the following paragraph).

Five measures each of the PDQ-39 and the COPM were administered with each participant during the baseline A phase to characterize each participant's self-perceived health-related quality of life related to their diagnosis and performance on self-selected task-oriented goals. The five measures took place over a two-week period, according to the following schedule: Monday, Wednesday, Friday, Tuesday, and Thursday. This schedule was chosen in order to capture as many potential variants as possible that may affect participants' baseline scores. For example, if a participant is scheduled to have a bath provided by home care workers

every Tuesday, and that participant is usually fatigued after having had a bath, that participant may score themselves lower on performance of task-oriented goals on Tuesdays than on other days of the week which are non-bath days. The first measure of the PDQ-39 and the COPM took place in the Movement Disorder Clinic occupational therapy treatment room at Deer Lodge Centre on a Monday and was completed prior to completing the participants' interviews. Participants were handed a PDQ-39 form by a research assistant and were asked to complete the measure independently, then were asked to hand the completed form back to the research assistant. The first measure of the COPM was completed in a semi-structured interview style administered by the principal investigator. Participants were given four copies each of the PDQ-39 and the COPM forms to complete at home according to the two-week schedule described above. Each paired copy of the PDQ-39 and the COPM were provided in envelopes labelled with the appropriate day of the week that corresponded with the date on which each pair of forms was to be completed. Four separate envelopes were used to discourage participants from looking back at their own responses on previously completed forms. This was done to reduce the influence of previous participant responses on later responses. Participants were given phone call reminders from a research assistant on Wednesday, Friday, Tuesday, and Thursday to complete the PDQ-39 and the COPM measures according to the schedule. Participants were asked to bring all completed forms from the pre-intervention *A* phase measures to their first treatment sessions at the start of the intervention *B* phase.

In an attempt to account for possible confounding factors related to life events that may occur during the pre-intervention *A* phase that may influence study results, the research assistant asked questions according to the script detailed in Appendix J on the final evaluation day.

In a similar fashion to the administration of the PDQ-39 with participants, participants' caregivers were first asked to come to the Movement Disorder Clinic occupational therapy treatment room at Deer Lodge Centre on a Monday (the same Monday as the participants, for everyone's convenience). The caregivers were handed a Zarit Burden Interview form by a research assistant and were asked to complete the measure independently, then were asked to hand the completed form back to the research assistant. Caregivers were given four copies of the Zarit Burden Interview to be completed at home according to the same two-week schedule as the baseline measures being completed by the participants, for a total of five measures of the Zarit Burden Interview during the baseline *A* phase. Each copy of the Zarit Burden Interview to be completed at home was provided in envelopes labelled with the appropriate day of the week that each form was to be completed on. Four separate envelopes were used to discourage caregivers from looking back at their own responses on forms they had completed on previous; this was done to reduce the influence of previous caregiver responses on later responses. Caregivers were given phone call reminders by a research assistant on Wednesday, Friday, Tuesday, and Thursday to complete the Zarit Burden Interview measures according to the schedule. Caregivers were asked to bring all completed forms from the pre-intervention *A* phase measures to their corresponding care recipients' first treatment session at the start of the intervention *B* phase.

In an attempt to account for possible confounding factors related to life events that may occur during the pre-intervention *A* phase that may influence study results, the research assistant phoned caregivers for their final reminder to complete the pre-intervention *A* phase measures, and asked questions according to the script detailed in Appendix K.

Clinical observations were documented in a field log during each interview session, as well as during the administration of the first measure of the COPM, by the principal investigator.

Following each data collection session that was administered by the principal investigator, the principal investigator also wrote entries into a reflective journal log.

3.4.5 Intervention B Phase

Each of the three participants were provided with individualized CO-OP treatment sessions provided by the principal investigator twice weekly for 45-60 minutes over a maximum of six weeks, for a total of twelve sessions. Treatment sessions were intended to end once the participant had achieved all five of his treatment goals, or once twelve treatment sessions had been completed, whichever occurred first. As part of the CO-OP treatment protocol, the COPM was administered to set treatment goals at the start of the first treatment session. Each participant's caregiver was required to attend treatment sessions to observe until at least one cycle of the “Goal- Plan- Do- Check” global strategy has been followed, so that each caregiver could become familiar with the treatment strategy in order to coach the participant when the participant utilized the strategy independently outside of treatment sessions. The caregiver was welcome to attend all remaining treatment session if both the caregiver and the participant wished, and in fact, all three caregivers chose to attend all treatment sessions.

CO-OP sessions focusing on the “Goal” and “Plan” steps of the CO-OP global strategy were held in the Movement Disorder Clinic occupational therapy treatment room at Deer Lodge Centre. CO-OP sessions focusing on the “Do” and “Check” steps of the global strategy were planned to be held in environmental setting most authentically appropriate to following through on the goal: such settings could have include the Movement Disorder Clinic (MDC) occupational therapy treatment room, the participant’s own home, or a third location out in the community, such as a grocery store, a library, or the participant’s workplace. This planned adjustment of treatment settings in accordance with the natural environmental settings specific to each client-

identified treatment goal is in line with CO-OP best practice guidelines (Polatajko, Green, & Bernie, 2013) and is similar to the study design used by Dawson, Gaya, Hunt, Levine, Lemsky, & Polatajko (2009) and Dawson, Binns, Hunt, Lemsky, & Polatajko (2013) in their examinations of adults with cognitive impairment related to chronic stroke symptoms. In actuality, most of the goals that participants chose to work on during treatment were not environmentally specific and therefore, most treatment sessions that took place in the MDC occupational therapy treatment room focused on all four steps of the CO-OP global strategy. For the few goals that were environmentally specific, the principal investigator offered to provide treatment sessions focusing on the “Do” and “Check” steps of the global strategy for those goals directly in the natural environments in which those goals would take place (the participants’ homes); however, after two in-home sessions for Participant 2 and one in-home session for Participant 3, both participants stated that they felt uncomfortable being directly observed while following through with the “Do” and “Check” steps and that they would prefer to complete their “Do” and “Check” steps on their own as homework. Therefore, the treatment approach was modified according to the participants’ preferences and their “Do” and “Check” homework was reviewed in the clinical setting at their next treatment sessions.

During the “Goal” step of the CO-OP participants were encouraged to identify five occupational performance issues they wished to set as treatment goals for performance improvement. Although previous studies of the use of the CO-OP in adults with cognitive impairment have identified up to nine treatment goals (Dawson, Gaya, Hunt, Levine, Lemsky, & Polatajko, 2009; Skidmore, Holm, Whyte, Dew, Dawson, & Becker, 2011), it was hypothesized by this author that any effects of the CO-OP on adults with cognitive impairment in Parkinson’s disease would be able to be observed with as few as five goals. This hypothesis was based in part

on the fact that 1) The COPM, which is integrated into the CO-OP treatment protocol as a goal-setting tool, is designed to address no more than five treatment goals (Law, Baptiste, Carswell, McColl, Polatajko, & Pollock, 2005); 2) the only best practice guidelines currently in place for the CO-OP treatment protocol (those for the pediatric population) recommend addressing only three treatment goals (Polatajko, Green, & Bernie, 2013; Polatajko & Mandich, 2004), 3) “the type and number of goals seems to be less important than the repetitive practice applying the meta-cognitive strategy to each goal,” (Skidmore, Holm, Whyte, Dew, Dawson, & Becker, 2011, p. 220), and 4) the three most recent published investigations on the use of the CO-OP with adults with cognitive impairment set fewer goals than the two earlier publications, with an average of 5-8 goals (Dawson, Binns, Hunt, Lemsky, & Polatajko, 2013; Ng, Polatajko, Marziali, Hunt, & Dawson, 2013; Poulin, Korner-Bitensky, Bherer, Lussier, & Dawson, 2016). If, during this study, the participant-identified treatment goals had been too large to be addressed within the confines of the CO-OP treatment protocol, participants would have been guided to break down their goals into more manageable components, as done in the study by Dawson, Gaya, Hunt, Levine, Lemsky, & Polatajko (2009). For example, if one participant’s goals had been to be able to improve his overall performance at his job, the participant may have been guided to describe his or her job’s major task components. The participant may then have been guided to develop a treatment goal related to one specific job task component that the participant considered to be the most important component needing improvement.

CO-OP sessions were provided twice weekly in accordance with the treatment frequency used with the CO-OP for adults with cognitive impairment in chronic traumatic brain injury (Dawson, Gaya, Hunt, Levine, Lemsky, & Polatajko, 2009; Dawson, Binns, Hunt, Lemsky, & Polatajko, 2013; Ng, Polatajko, Marzilali, Hunt, & Dawson, 2013). This treatment frequency was

used because the chronic traumatic brain injury population is the most similar to the Parkinson's population of the published studies to date using adult populations, and because there are no best practice guidelines for frequency of CO-OP intervention sessions (Polatajko, Green, & Bernie, 2013; Polatajko & Mandich, 2004). In accordance with CO-OP best practice guidelines (Polatajko, Green, & Bernie, 2013; Polatajko & Mandich, 2004), treatment sessions for any one participant were stopped once that participant had achieved all five of their treatment goals if their treatment goals had all been achieved prior to completing twelve treatment sessions.

It was intended for the participants to be given the PDQ-39 forms and the COPM forms and for the caregivers to be given the ZBI forms five more times each at home on their own, according to the following schedule: between treatment sessions 2 & 3, 4 & 5, 6 & 7, 8 & 9, and 10 & 11. In actuality, each measure was completed only four more times with each participant and caregiver since treatment did not continue for any participant beyond eight treatment sessions (the smallest number of sessions needed was seven). The participants and caregivers were asked to bring each completed form for the PDQ-39, COPM, and ZBI back at the next treatment session.

In-depth semi-structured interviews were administered by the principal investigator one-on-one with each participant and each caregiver once at the mid-way point of the intervention phase (intended to take place between CO-OP sessions six and seven, but when participants appeared to be progressing more quickly through their treatment goals than the principal investigator had anticipated in comparison to the timeline documented in other studies of the CO-OP in adult populations, the interventions were rescheduled to take place between CO-OP sessions four and five). The interviews were audio recorded with two digital recorders (two recorders were used in case of failure of one recorder).

Direct observation records were documented in a field log by the principal investigator during each *B* phase data collection session. Following each treatment session and data collection session, the principal investigator wrote entries into a reflective journal log.

The first three CO-OP treatment sessions for each participant were video recorded. The video recordings were debriefed with another researcher to ensure the integrity of the CO-OP protocol was maintained as well as possible by the principal investigator.

3.4.6 Post-Intervention A Phase

As the final component of the CO-OP treatment protocol, the COPM was re-administered with each participant individually during his final individual treatment session to determine if and how well the treatment goals had been met.

As done in the pre-intervention A phase, five measures each of the PDQ-39 and the COPM were administered with each participant during the post-intervention A phase to characterize each participant's subjective health-related quality of life related to their diagnosis and performance on self-selected task-oriented goals. The five measures took place according to the same two-week schedule outlined in the pre-intervention A phase (Monday, Wednesday, Friday, Tuesday, Thursday) in order to capture as many potential variants as possible that may affect participants' score patterns. The first measure of the PDQ-39 and the COPM took place in the Movement Disorder Clinic occupational therapy treatment room at Deer Lodge Centre on a Monday. Participants were handed a PDQ-39 form and a COPM form by the principal investigator and were asked to complete the measures independently, then to hand the completed forms back to the principal investigator. Participants were then given four more copies each of the PDQ-39 and the COPM forms to complete at home according to the two-week schedule described above. Each paired copy of the PDQ-39 and the COPM were provided in envelopes

labelled with the appropriate day of the week that each pair of forms was to be completed on. Four separate envelopes were used to discourage participants from looking back at their own responses on forms they had completed on previous days when completing the forms for the current day. Participants were given phone call reminders from a research assistant on Wednesday, Friday, Tuesday, and Thursday to complete the PDQ-39 and the COPM measures according to the schedule. Participants were asked to bring all completed forms from the post-intervention A phase measures to their post-intervention A phase interview session.

In a similar fashion to the administration of the PDQ-39 and COPM with participants during the post-intervention A phase, participants' caregivers were asked to come to the Movement Disorder Clinic occupational therapy treatment room at Deer Lodge Centre on a Monday (the same Monday as the participants, for everyone's convenience). The caregivers were handed a Zarit Burden Interview form by a research participant and were asked to complete the measure independently, then to hand the completed form back to the research assistant. Caregivers were given four copies of the Zarit Burden Interview to be completed at home according to the same two-week schedule that was followed in the pre-intervention A phase, for a total of five measures of the Zarit Burden Interview during the post-intervention A phase. Caregivers were given phone call reminders by a research assistant on Wednesday, Friday, Tuesday, and Thursday to complete the Zarit Burden Interview measures according to the schedule. Caregivers were asked to bring all completed forms from the post-intervention A phase measures to their post-intervention A phase interview.

In an attempt to account for possible confounding factors related to life events that may have occurred during the post-intervention A phase that may influence study results, the research assistant phoned participants and caregivers for their final reminders to complete the post-

intervention A phase measures and asked the participants and caregivers the same questions that had been asked by at the end of the pre-intervention A phase (see Appendix J for questions asked of the participants and Appendix K for questions asked of the caregivers).

At the end of the post-intervention A phase, in-depth semi-structured interview sessions were administered by the principal investigator one-on-one with each participant and their caregiver / significant other separately. All interview sessions were held in the Movement Disorder Clinic occupational therapy treatment room at Deer Lodge Centre and were audio recorded.

Direct observation records were taken during each post-intervention A phase data collection session and were recorded in a field log by the principal investigator. Following each post-intervention A phase data collection session, the principal investigator wrote entries into a reflective journal log.

3.4.7 Three-Month Follow-Up

After a time period of three months post-intervention, participants and their caregivers were asked to return for a final phase of data collection in the Movement Disorder Clinic occupational therapy treatment room at Deer Lodge Centre. The participants were asked to complete one copy of the PDQ-39 form independently (PDQ-39 form was handed to them by a research assistant, then the participants were asked to hand back the completed form) and the COPM in a semi-structured interview with the principal investigator. As stated in section 3.4.3, the MoCA and the Stroop test were re-administered with the participants at the 3-month follow-up to ensure that no rapid deterioration in participant cognition occurred during the study observation period. The re-administration of the MoCA and the Stroop test was done by a

research assistant. The caregivers were asked by a research assistant to complete one copy of the Zarit Burden Interview questionnaire independently, then to hand back the completed form.

In an attempt to account for possible confounding factors related to life events that may have occurred at the time of the three-month follow-up that may influence study results, the research assistant asked the participants and caregivers the same questions that were asked at the end of the pre-intervention A phase (see Appendix J for questions asked of the participants and Appendix K for questions asked of the caregivers). For consistency with the pre- and post-intervention A phases, the questions were asked in relation to the previous two weeks.

In-depth semi-structured interview sessions were then administered by the principal investigator one-on-one with each participant and caregiver separately. Interview questions were identical to those used in the post-intervention participant and caregiver interview guides.

Direct observation records were taken during each follow-up data collection session and were recorded in a field log by the principal investigator. After each follow-up data collection session, the principal investigator wrote entries into a reflective journal log.

3.5 Analysis

3.5.1 Quantitative Data Analysis

Analysis of quantitative data involved both statistical and visual analysis. The standard deviation band method and a celeration line were used to compare participants' performance on and satisfaction with self-identified goals using the COPM and total health-related quality of life scores using the PDQ-39, during the baseline phase to the intervention phase, post-intervention phase, and follow-up phase (McEwen, Polatajko, Huijbregts, & Ryan, 2009 & 2010). The

standard deviation band method and the celeration line were also used to compare caregivers' scores on the ZBI during the baseline phase to the intervention phase, post-intervention phase, and follow-up phase. The data collected with the COPM, the PDQ-39, and the ZBI were also visually analyzed for each individual participant and caregiver.

Traditionally, single-subject studies have utilized visual analysis to analyze data (Gingerich, 1983). In the past, the lack of formal rules for data interpretation with visual analysis resulted in poor inter-rater reliability (Nourbakhsh & Ottenbacher, 1994). The primary advantage of visual analysis without following formal interpretation rules is its insensitivity to small or weak treatment effects that may be statistically significant but do not reach clinical significance (Nourbakhsh & Ottenbacher, 1994; Portney & Watkins, 2009). To improve upon interpretation inconsistencies, statistical analysis methods have been developed for use in single-subject research (Nourbakhsh & Ottenbacher, 1994).

When analyzing data from a single-subject case study, the two-standard deviation band method as well as a celeration line are often used in order to describe data trends (Fetters & Tilson, 2012; Portney & Watkins, 2009). To calculate the two-standard deviation band, the mean and standard deviation of the baseline data are calculated, then parallel lines representing two standard deviations above and two standard deviations below the mean are drawn horizontally through the baseline and intervention phases of the graph. The intervention is considered statistically significant if two or more data points fall above or below the two-standard deviation band in the intervention phase of the graph (Fetters & Tilson, 2012). In this study, since the standard deviation bands for all measures generally became much narrower in phases following the pre-intervention phase, the single standard deviation band method was used to analyze the data rather than the two-standard deviation band method. To calculate the single standard

deviation band, the mean and standard deviation of the pre-intervention phase data were calculated, then parallel lines representing one standard deviation above and one standard deviation below the mean were drawn horizontally through the baseline phase. The standard deviation band was also calculated for the intervention and post-intervention phases of the graph. A meaningful difference between dependent measures across phases was considered to have occurred if the upper and lower limits of the standard deviation bands for each phase did not overlap (Bloom, Fischer, & Orme, 2006).

The standard deviation band method was appropriate to be used with most quantitative data that was collected in this study, since the baseline data was normally distributed for most measures and data was usually stable with no obvious trend (Anastas, 1999; Nourbakhsh & Ottenbacher, 1994), with the exception of baseline COPM satisfaction scores for Participant 2 that trended upward. For data that was not distributed normally, the interquartile band method was the more appropriate choice over the standard deviation band method (Bloom, Fischer, & Orme, 2006). To calculate the interquartile bands, the scores at the 25th percentile, the 75th percentile, and the median score were each calculated within each data phase. Parallel lines representing the 25th percentile, the 75th percentile, and the median score were drawn horizontally across each data phase, creating interquartile bands. Meaningful change between phases was considered to have taken place if the interquartile bands between phases did not overlap (Bloom, Fischer, & Orme, 2006).

A celeration line represents the linear trend and slope of the data and allows interpretation of the acceleration or deceleration of the data (Portney & Watkins, 2009). The most common way to calculate a celeration line is by the split middle method (Ottenbacher, 1986). The split middle calculation method is done by plotting all the data points on a graph, then drawing a solid

vertical line at the median value of the baseline phase (or if there is an even number of data points, the line is drawn to separate the first half of the data points from the second half of the data points). Each of the two halves of the baseline phase are divided in half again using dashed vertical lines, and the median data point is determined for each half of the data in the baseline phase. Next, a straight line is drawn through the median data points of the first and second halves of the baseline phase. The line should be adjusted up or down so that it comes as close as possible to dividing the baseline data equally, with half the data points above the line and half the data points below the line, although the adjusted line must remain parallel with the original line. The celeration line is then extended into subsequent data phases to compare the predicted data line trend with the actual data that was collected (Ottenbacher, 1986). It is recommended that a celeration line only be used when there is a minimum of 7-9 data points in each data collection phase (Ottenbacher, 1986); therefore, results from celeration line calculations completed in this study must be interpreted with caution, as only 4-5 data points were collected in each phase.

Since the data points for each measure on each individual were likely to have been autocorrelated with each other data point for that individual on the particular measure in question, use of the C statistic to estimate data trends in the study would have been appropriate because the C statistic “is not affected by autocorrelation in the data series,” (Portney & Watkins, 2009, p. 262). Unfortunately, the C statistic could not be used in this study because it cannot be calculated with fewer than 8 data points in any one data collection phase (Backman & Harris, 1999; Ottenbacher, 1986).

Multiple approaches to single-subject data analysis using both statistical analysis and visual analysis are important (Kazdin, 2011; Nourbakhsh & Ottenbacher, 1994) because “there is limited consistency across different quantitative methods of analyzing single-subject data (and)

statistical analysis of single-subject data should not be viewed as a replacement for visual analysis,” (Nourbakhsh & Ottenbacher, 1994, p. 775). Statistical analysis is sensitive enough to detect subtle results that may be statistically significant, while visual analysis can be used to judge if the results are clinically significant.

3.5.2 Qualitative Data Analysis

Qualitative data from the in-depth interviews were analyzed using interpretive description methodology, which has its foundation in naturalistic epistemology (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). Interpretive description is an inductive qualitative data analysis method intended to examine a clinical phenomenon of interest in which patterns and themes from subjective perspectives can be put together to create a comprehensive, contextual interpretive description that can inform and guide clinical practice (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). Generalizations (theories) gleaned from interpretive description may also be tested in future, larger experimental studies (Biglan, Ary, & Wagenaar, 2000; DePoy & Gitlin, 2005). In order to maximize the comprehensiveness and contextualization of interpretations of the phenomenon being examined, interpretive description is designed to analyze small sample sizes and usually involves the use of multiple data collection methods, particularly interviews, observational records, and reflective journal logs (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). Interpretive description is useful to obtain maximum variation on any themes that may develop from the inductive analysis process (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997), and therefore interpretive description was ideal for investigating the study's research question since no information was yet known about the effect of the CO-OP on individuals with Parkinson's disease-related cognitive impairment, and the range of experiences and perspectives

of each study participant could not possibly be known prior to beginning data collection (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997).

At the start of the interpretive description analysis process, each interview was transcribed verbatim from its digital audio recording. Next, transcripts were read and re-read several times in order to identify interesting statements related to the research question. Once identified, these statements were coded and labelled with descriptive words or phrases. Codes were read and re-read in order to find patterns, and then these patterns were organized into categories and themes. Transcripts were then read through again to find any remaining uncoded or unsorted statements of interest to the research question. These remaining statements were also coded and categorized according to the patterns and themes that had emerged earlier, but the principal investigator was mindful also to attempt to allow new themes and categories to develop with each re-reading of the transcripts rather than to try to fit all interesting statements into the first few themes and categories that had developed. Any overlap across emerging themes and categories was identified and closely related themes and categories were collapsed together.

To maintain rigour and credibility of the decisions made during data analysis, the principal investigator took care to shift back and forth multiple times between examination of the data collected in the transcripts to the patterns and themes that emerged during the analysis process, allowing the data and the analysis to inform each other iteratively as is required in interpretive description (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). As the qualitative data analysis progressed, themes emerged which were later combined together with results from quantitative data analysis in order to make more abstract generalizations (theories) to explain the data gathered on each participant/caregiver case and also to explain the data gathered on the participants as a group and the caregivers as a group (Luborsky & Lysack, 2006). In addition to

the iterative process of shifting back and forth between examination of the interview data and the analysis process itself, rigour was maintained by debriefing with a thesis committee member (Dr. Jacquie Ripat) with an expertise in qualitative analysis in order to triangulate results, and by maintaining an audit trail of all qualitative documentation to track the analytic reasoning process and to verify that the analysis that was done and the generalizations (theories) that were generated were grounded within the data (Lysack, Luborsky, & Dillaway, 2006; Thorne, Reimer Kirkham, & MacDonald-Emes, 1997; Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). Qualitative data from the direct observation records and from the reflective journal log further informed and verified results from interpretive description analysis of data from the in-depth interviews.

3.5.3 Combining Quantitative and Qualitative Data Analysis

The qualitative data gathered in the study was used to elaborate on and explain the quantitative data, merging the data analysis as is done in a mixed methods approach (Creswell, 2009). Specifically, results from quantitative data analysis of COPM scores, PDQ-39 scores, and ZBI scores were examined in context of results from qualitative analysis of in-depth interviews and were further informed by information from observation records and the reflective journal log.

4.0 RESULTS

4.1 Demographic and Descriptive Characteristics

The three individuals with Parkinson's disease who participated in this study were all males, ranging in age from 69 to 84. For each participant with Parkinson's disease, their wives participated in the study as the respective caregivers. Screening measures were the MoCA, Schwab & England ADL Scale, BDI, and Hoehn & Yahr Scale. The Stroop test (colour-name, word, and colour-word) was also collected. These measures were completed with each participant with Parkinson's disease and again at the three-month follow-up. Caregivers completed the MoCA once only, during screening (see *Table 4.1*).

Table 4.1 Participant Demographic and Descriptive Characteristics

Variable	Participant 1		Participant 2		Participant 3	
	Screening	Follow-Up	Screening	Follow-Up	Screening	Follow-Up
Gender	Male		Male		Male	
Age	75		83		69	
MoCA score	18/30	18/30	20/30	21/30	19/30	20/30
BDI Score	15/63	21/63	9/63	7/63	4/63	7/63
Schwab & England ADL Scale score	90%	90%	90%	90%	90%	90%
Hoehn & Yahr Scale score	2	2	1	1	1	2
Stroop colour-name score	44	38	39	28	47	50
Stroop word score	78	73	41	46	70	76
Stroop colour-word score	18	20	17	9	20	14
	Caregiver 1		Caregiver 2		Caregiver 3	
Gender	Female		Female		Female	
MoCA score	17*/30		28/30		24/30	

* One point added for education < grade 12

4.1.1 Case 1: Participant 1 and Caregiver 1 Demographic and Descriptive Characteristics at Pre-intervention and at Three Month Follow-up

Participant 1 was 75 years old during his participation in the CO-OP treatment program. Pre-intervention screening suggested that he was experiencing mild cognitive impairment, as measured using the MoCA with a score of 18/30. Participant 1's MoCA score at three month follow-up was unchanged from his pre-intervention MoCA score, suggesting no further deterioration in cognition occurred during the study period. Pre-intervention, Participant 1's BDI score was 15/63, which suggested he did not have symptoms of depression; however, his BDI score three months following treatment was 21/63, suggesting moderate clinical depression. Participant 1's Schwab & England ADL Scale score was 90% at pre-intervention screening and three months following treatment, indicating that at pre-intervention Participant 1 felt that he was completely independent with activities of daily living but with some degree of slowness and difficulty, and suggesting that no deterioration had taken place in regard to Participant 1's feelings about his independence with activities of daily living during the study period. Participant 1's Hoehn & Yahr Scale score was 2 at pre-intervention screening and three months following treatment, indicating that Participant 1's Parkinson's symptoms affected both sides of his body but did not affect his balance prior to treatment, and that no further progression of physical symptoms of Parkinson's had taken place during the study period. Participant 1's score on the Stroop colour-name test at three month follow-up was 14% worse than pre-intervention, his score on the Stroop word test at three month follow-up was 6% worse than at pre-intervention, and his score on the Stroop colour-word test at three month follow-up was 11% better than at pre-intervention, suggesting that Participant 1's cognitive performance related to inhibition had not changed during the study period. Pre-intervention screening suggested that Caregiver 1 was

also experiencing mild cognitive impairment, as indicated by her 17/30 score on the MoCA, which was one point lower than Participant 1's MoCA score and very close to the 16/30 cut off that would suggest possible dementia.

4.1.2 Case 2: Participant 2 and Caregiver 2 Demographic and Descriptive Characteristics at Pre-intervention and at Three Month Follow-up

Participant 2 was 83 years old during his participation in the CO-OP treatment program. Pre-intervention screening suggested that he was experiencing mild cognitive impairment, as measured using the MoCA with a score of 20/30. Participant 2's MoCA score at three month follow-up was 21/30, suggesting no further deterioration in cognition occurred during the study period. Participant 2's BDI score was 9/63 pre-intervention and 7/63 at three month follow-up, suggesting that Participant 2's did not have symptoms of depression either prior to treatment or three months following treatment. Participant 2's Schwab & England ADL Scale score was 90% at pre-intervention screening and three months following treatment, indicating that at pre-intervention Participant 2 felt that he was completely independent with activities of daily living but with some degree of slowness and difficulty, and suggesting that no deterioration had taken place in regard to Participant 2's feelings about his independence with activities of daily living during the study period. Participant 2's Hoehn & Yahr Scale score was 1 at pre-intervention screening and three months following treatment, indicating that Participant 2's Parkinson's symptoms affected only one of his body and caused minimal to no functional disability prior to treatment, and that no further progression of physical symptoms of Parkinson's had taken place during the study period. Participant 2's score on the Stroop colour-name test at three month follow-up was 28% worse than pre-intervention, his score on the Stroop word test at three month

follow-up was 12% better than at pre-intervention, and his score on the Stroop colour-word test at three month follow-up was 47% worse than at pre-intervention, suggesting that Participant 2's cognitive performance related to inhibition may have worsened during the study period. Pre-intervention screening suggested that Caregiver 2's cognition was normal, as indicated by her 28/30 score on the MoCA.

4.1.3 Case 3: Participant 3 and Caregiver 3 Demographic and Descriptive Characteristics at Pre-intervention and at Three Month Follow-up

Participant 3 was 69 years old during his participation in the CO-OP treatment program. Pre-intervention screening suggested that he was experiencing mild cognitive impairment, as measured using the MoCA with a score of 19/30. Participant 3's MoCA score at three month follow-up was 20/30, suggesting no further deterioration in cognition occurred during the study period. Participant 3's BDI score was 4/63 pre-intervention and 7/63 at three month follow-up, suggesting that Participant 3's did not have symptoms of depression either prior to treatment or three months following treatment. Participant 3's Schwab & England ADL Scale score was 90% at pre-intervention screening and at three months following treatment, indicating that at pre-intervention Participant 3 felt that he was completely independent with activities of daily living but with some degree of slowness and difficulty, and suggesting that no deterioration had taken place in regard to Participant 3's feelings about his independence with activities of daily living during the study period. Participant 3's Hoehn & Yahr Scale score was 1 at pre-intervention screening and 2 three months following treatment, indicating that Participant 2's physical Parkinson's symptoms had affected only one of his body prior to treatment, but that his symptoms had progressed to affect both sides of his body by three months following treatment,

although his balance was not yet affected. Participant 3's score on the Stroop colour-name test at three month follow-up was 6% better than pre-intervention, his score on the Stroop word test at three month follow-up was 9% better than at pre-intervention, and his score on the Stroop colour-word test at three month follow-up was 30% worse than at pre-intervention, suggesting that Participant 3's cognitive performance related to inhibition may have worsened during the study period. Pre-intervention screening suggested that Caregiver 3 was also experiencing mild cognitive impairment, as indicated by her 24/30 score on the MoCA.

4.2 Quantitative Data

4.2.1 Canadian Occupational Performance Measure (COPM)

The COPM was completed five times in the pre-intervention *A* phase, four times in the intervention *B* phase, five times in the post-intervention *A* phase, and once at the three month follow-up with each participant with Parkinson's disease. The average performance score is an average of the self-rated performance scores that participants identified for each of their five treatment goals. The average satisfaction score is an average of the self-rated satisfaction scores that participants identified for their self-perceived performance level on each of their five treatment goals.

Statistical analysis found that the data collected with Participant 1 and with Participant 2 was normally distributed for the COPM average performance scores and the COPM average satisfaction scores throughout the pre-intervention, intervention, and post-intervention phases. The data collected with Participant 3 was not normally distributed on the COPM average performance scores throughout the pre-intervention, intervention, or post-intervention phases. The data collected with Participant 3 was normally distributed on the COPM average satisfaction

scores in the pre-intervention or intervention phases, but was not normally distributed in the post-intervention phase.

The following table describes the treatment goals self-identified by participants the first time the COPM was administered:

Table 4.2 COPM Goals

Participant	Trained Goals	Untrained Goals
Participant 1	<ol style="list-style-type: none"> 1. To remember names of familiar people 2. To remember details of conversation 3. To remember what is next on a travel route 	<ol style="list-style-type: none"> 4. To be more involved in interactions in social settings. 5. To keep my computers operating at the level they are meant to provide.
Participant 2	<ol style="list-style-type: none"> 1. To not make more than one or two spelling mistakes on emails. 2. To make my emails more complete without missing information. 3. To improve my capacity to come to decisions. 	<ol style="list-style-type: none"> 4. To be able to get through the 2013 version of Quicken and get familiar with it. 5. To improve my ability to remember what people have said in conversation so I can respond back.
Participant 3	<ol style="list-style-type: none"> 1. To be aware of the correct day of the week and the correct date on the calendar. 2. To take my medication on time for all five doses in one day. 3. To be more reliable with remembering to put things back where they belong (at home). 	<ol style="list-style-type: none"> 4. To improve my skills with navigating while driving. 5. To remember which colour I'm shooting when playing pool (stripes or solids).

On the following pages, *Tables 4.3, 4.4, and 4.5* outline the COPM average performance scores and average satisfaction scores at each measurement point for Participants 1, 2, and 3 respectively, with each table followed by figures that illustrate the standard deviation band / interquartile band calculations and celeration line calculations for each set of scores for each individual participant.

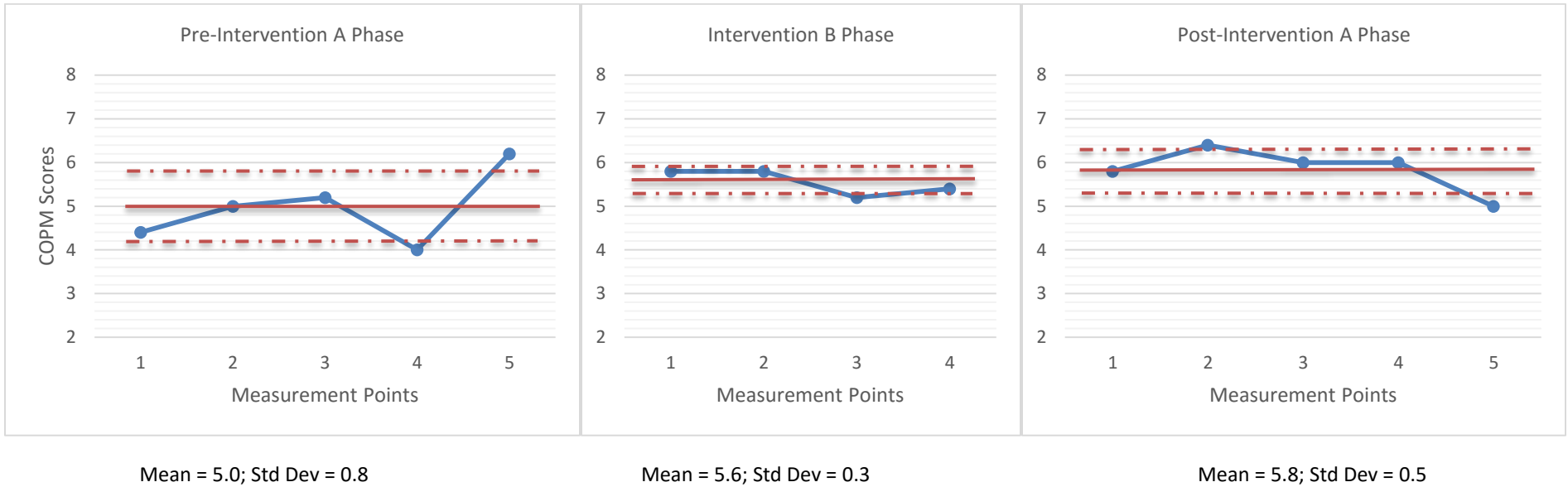
Table 4.3 COPM Scores for Participant 1

Measurement Point	Average Performance Score	Average Satisfaction Score
Pre-A1	4.4	4.8
Pre-A2	5.0	5.4
Pre-A3	5.2	5.4
Pre-A4	4.0	4.0
Pre-A5	6.2	5.8
B1	5.8	5.6
B2	5.8	5.2
B3	5.2	4.8
B4	5.4	6.0
Post-A1	5.8	5.4
Post-A2	6.4	5.8
Post-A3	6.0	5.6
Post-A4	6.0	6.4
Post-A5	5.0	5.0
3 Month F/U	3.8	3.2

COPM Performance Scores: average pre-intervention phase scores = 5.0; average intervention phase scores = 5.6; average post-intervention phase scores = 5.8; three month follow-up score = 3.8.

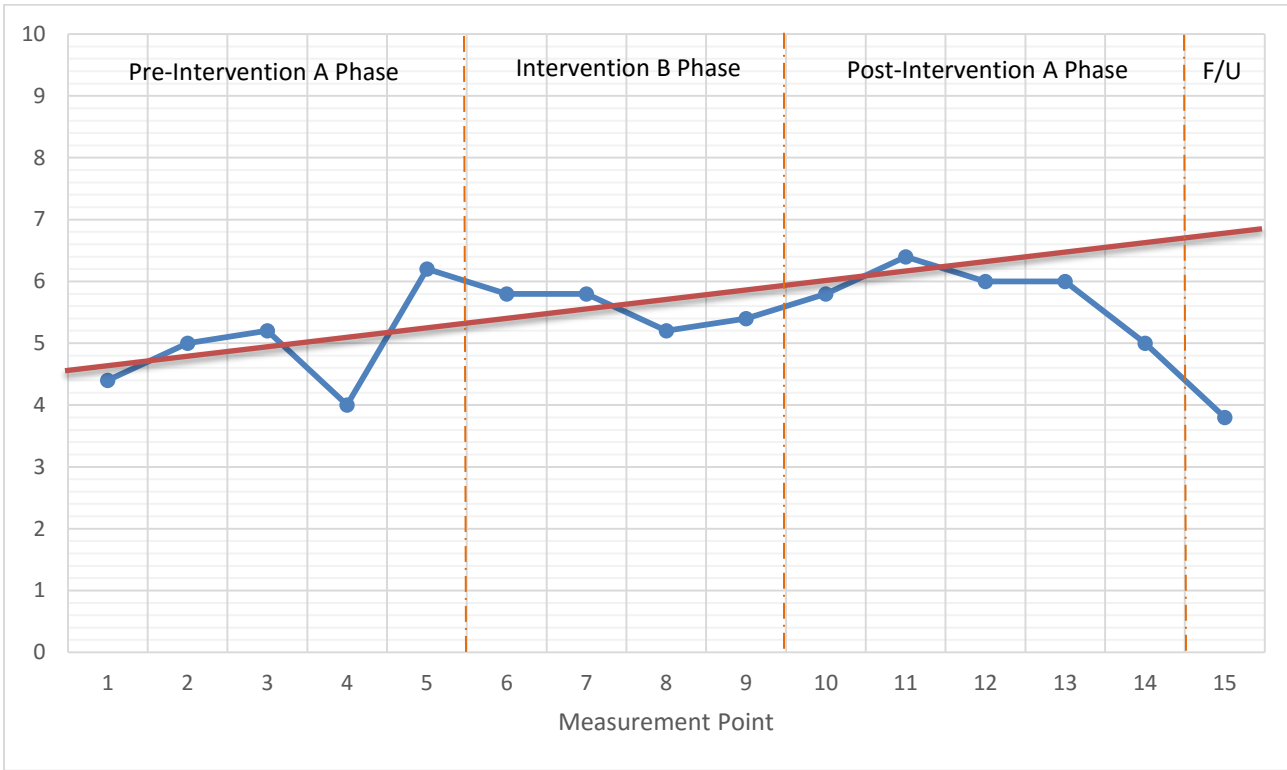
COPM Satisfaction Scores: average pre-intervention phase scores = 5.1; average intervention phase scores = 5.6; average post-intervention phase scores = 5.6; three month follow-up score = 3.2.

Figure 2 Standard Deviation Band Calculations for Participant 1 COPM Performance Scores



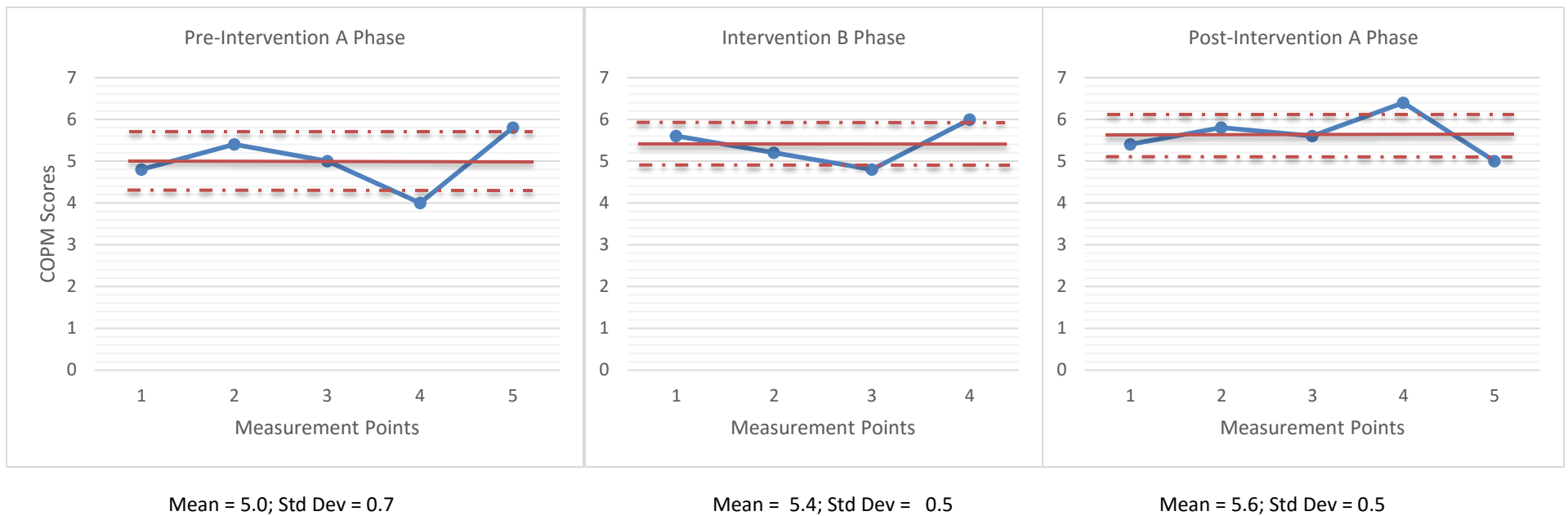
The upper and lower limits of the standard deviation bands for each phase overlap, suggesting there was not a statistically significant difference in COPM performance scores across phases for Participant 1.

Figure 3 Celeration Line - Split Middle Method - for Participant 1 COPM Performance Scores



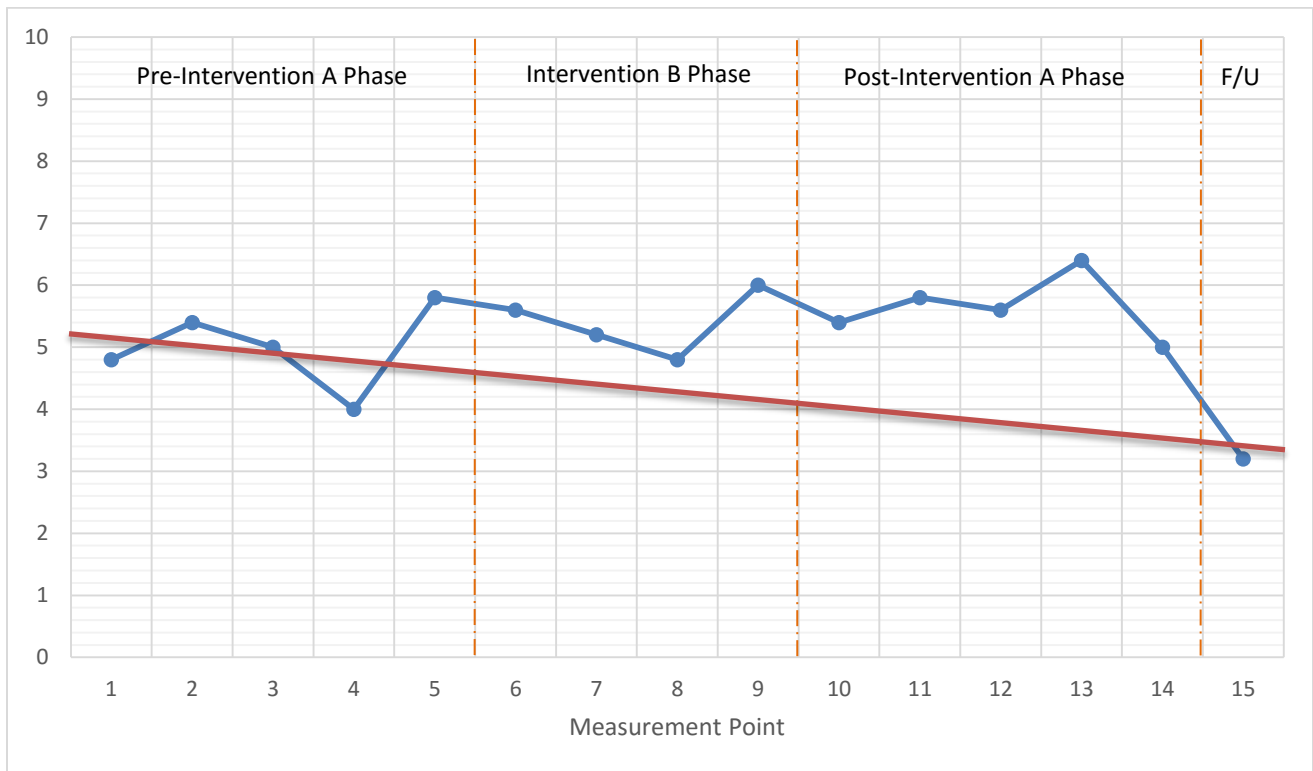
Data points follow the baseline celeration line until the latter two points of the post-intervention phase and the follow-up phase, at which point the data trends downward. This suggests there was not a statistically significant difference in COPM performance scores for Participant 1 from what was expected until COPM scores decreased below expectations in the latter portion of the post-intervention phase and the three month follow-up phase.

Figure 4 Standard Deviation Band Calculations for Participant 1 COPM Satisfaction Scores



The upper and lower limits of the standard deviation bands for each phase overlap, suggesting there was not a statistically significant difference in COPM satisfaction scores across phases for Participant 1.

Figure 5 Celeration Line - Split Middle Method - for Participant 1 COPM Satisfaction Scores



Data points fell above the baseline celeration line for the intervention and post-intervention phases, but the three month follow-up data point returned to the celeration trend line. This suggests that there was a statistically significant difference in COPM satisfaction scores across phases for Participant 1 that was higher than expected until scores lowered back to expectations the three month follow-up.

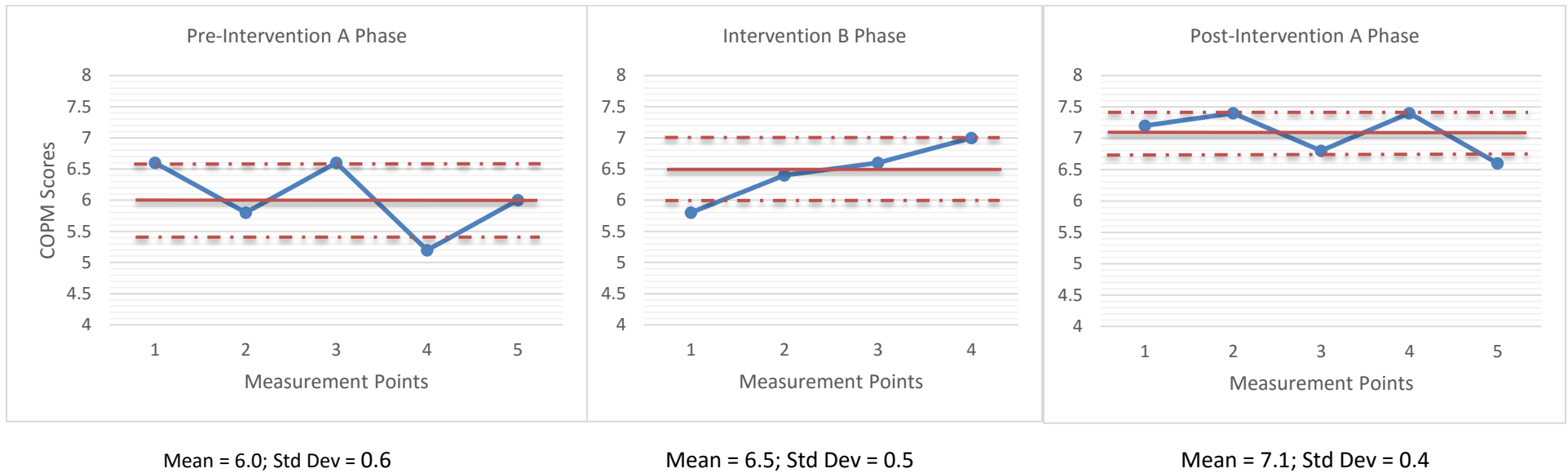
Table 4.4 COPM Scores for Participant 2

Measurement Point	Average Performance Score	Average Satisfaction Score
Pre-A1	6.6	3.4
Pre-A2	5.8	5.0
Pre-A3	6.6	5.6
Pre-A4	5.2	7.2
Pre-A5	6.0	5.8
B1	5.8	6.0
B2	6.4	6.8
B3	6.6	7.6
B4	7.0	8.0
Post-A1	7.2	8.2
Post-A2	7.4	7.8
Post-A3	6.8	7.2
Post-A4	7.4	6.4
Post-A5	6.6	7.0
3 Month F/U	8.0	8.2

COPM Performance Scores: average pre-intervention phase scores = 6.0; average intervention phase scores = 6.5; average post-intervention phase scores = 7.1; three month follow-up score = 8.0.

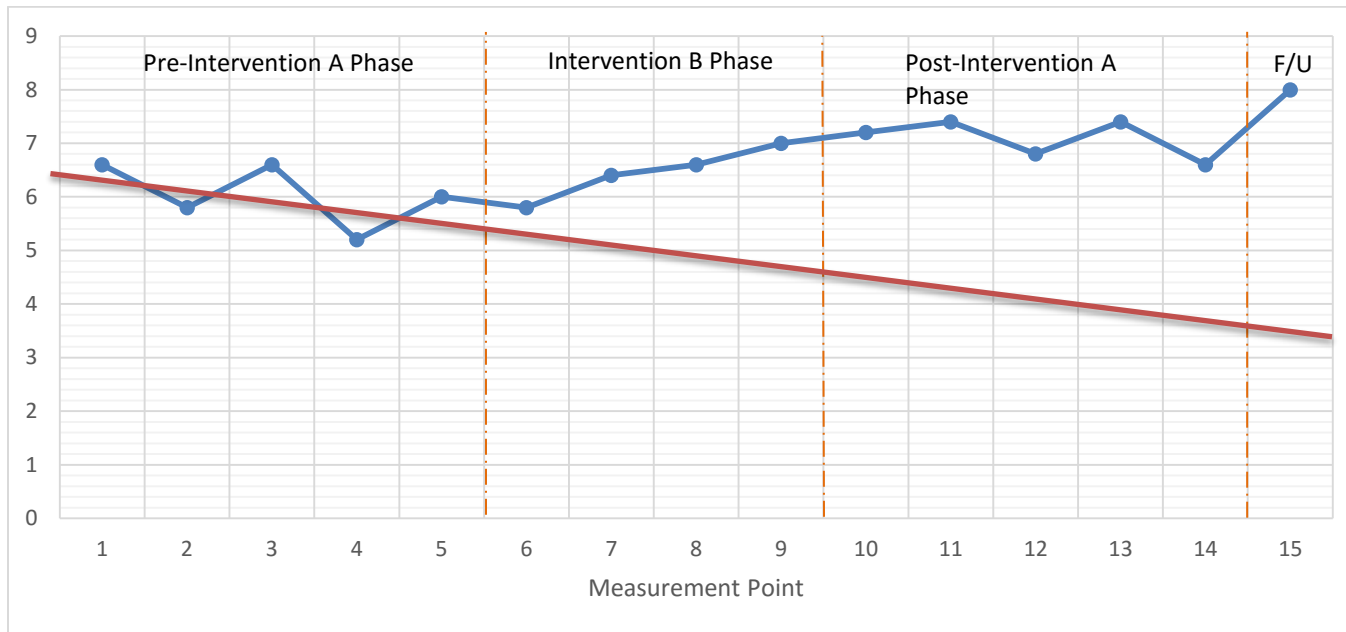
COPM Satisfaction Scores: average pre-intervention phase scores = 5.4; average intervention phase scores = 7.1; average post-intervention phase scores = 7.3; three month follow-up score = 8.2.

Figure 6 Standard Deviation Band Calculations for Participant 2 COPM Performance Scores



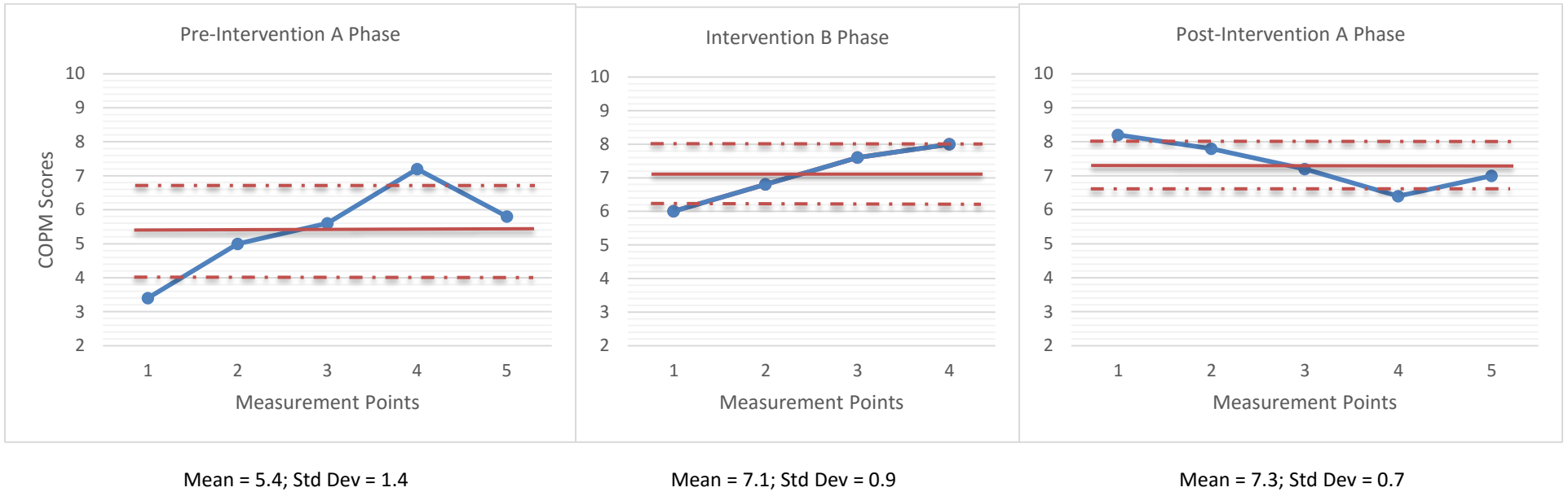
The upper and lower limits of the standard deviation bands for the pre-intervention and post-intervention phases do not overlap, suggesting there was a statistically significant increase in COPM performance scores across phases for Participant 2.

Figure 7 Celeration Line - Split Middle Method - for Participant 2 COPM Performance Scores



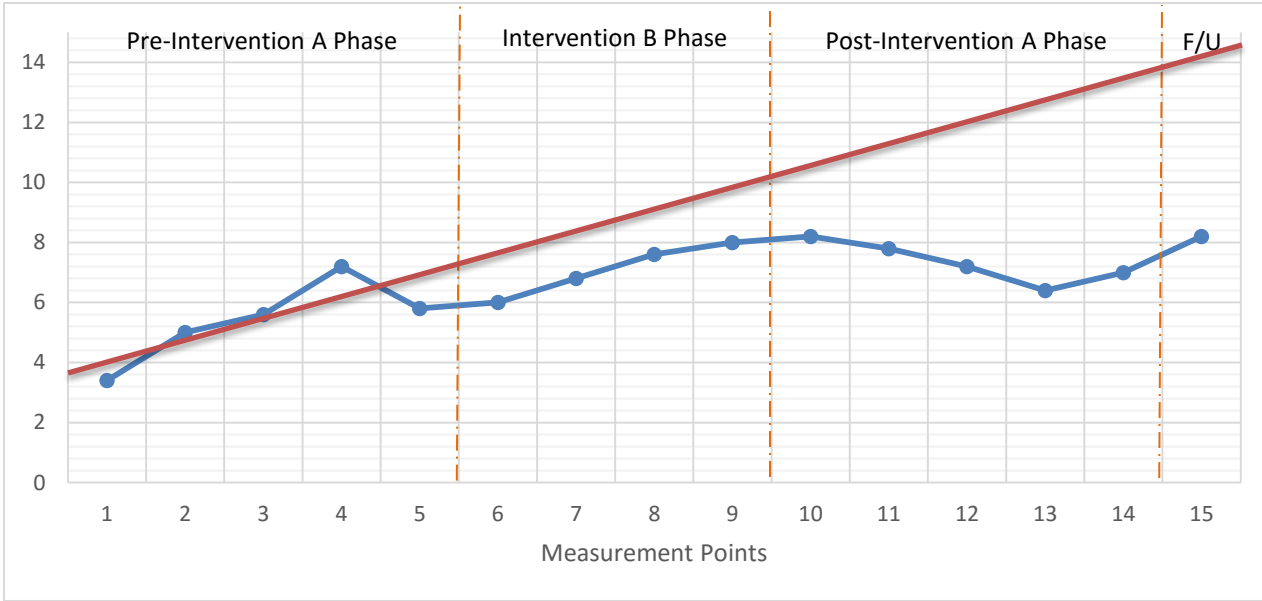
Data points fell above the baseline celeration line in the intervention, post-intervention, and follow-up phases. This suggests that there was a statistically significant increase in COPM performance scores for Participant 2 compared to what was expected beyond the pre-intervention phase.

Figure 8 Standard Deviation Band Calculations for Participant 2 COPM Satisfaction Scores



The upper and lower limits of the standard deviation bands between phases overlap, suggesting there was not a statistically significant difference in COPM satisfaction scores across phases for Participant 2. Data in the pre-intervention A phase was unstable, with an upward trend.

Figure 9 Celeration Line - Split Middle Method - for Participant 2 COPM Satisfaction Scores



Data points fell below the baseline celeration line trend in the intervention, post-intervention, and follow-up phases. This suggests that there was a statistically significant difference in COPM satisfaction scores for Participant 2 in that scores were lower than expected beyond the pre-intervention phase; however, celeration line predicts impossibly high COPM scores beyond the intervention phase, as the COPM scale does not go above 10.

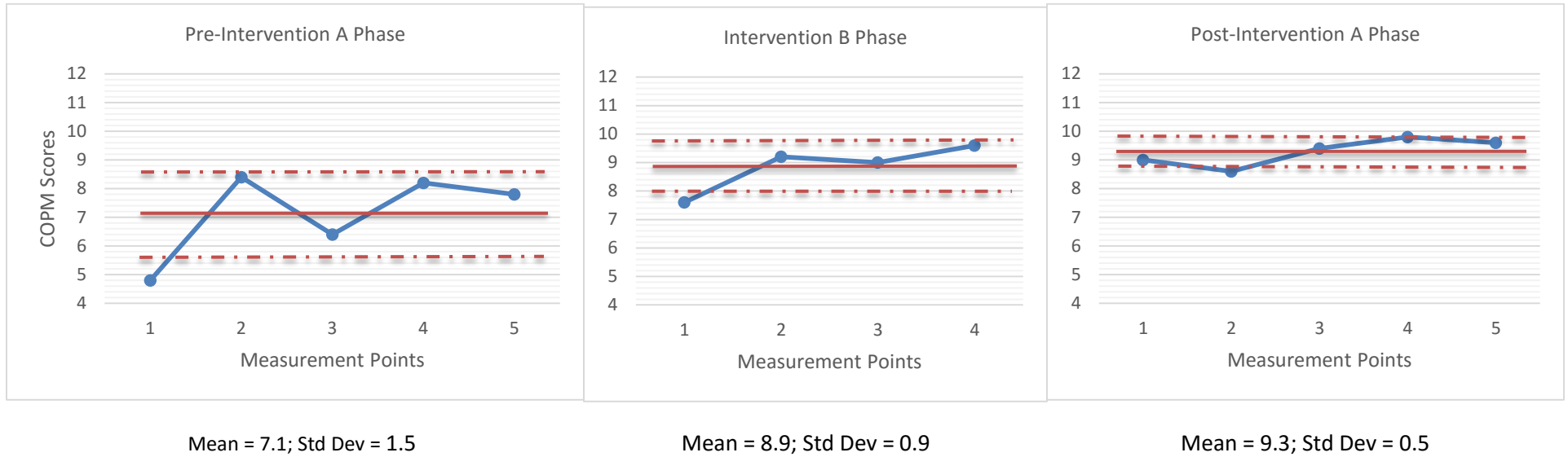
Table 4.5 COPM Scores for Participant 3

Measurement Point	Average Performance Score	Average Satisfaction Score
Pre-A1	4.8	3.6
Pre-A2	8.4	8.8
Pre-A3	6.4	8.8
Pre-A4	8.2	7.2
Pre-A5	7.8	7.2
B1	7.6	7.6
B2	9.2	9.2
B3	9.0	9.2
B4	9.6	9.6
Post-A1	9.0	9.4
Post-A2	8.6	8.8
Post-A3	9.4	9.4
Post-A4	9.8	9.6
Post-A5	9.6	9.6
3 Month F/U	7.2	6.0

COPM Performance Scores: average pre-intervention phase scores = 7.1; average intervention phase scores = 8.9; average post-intervention phase scores = 9.3; three month follow-up score = 7.2.

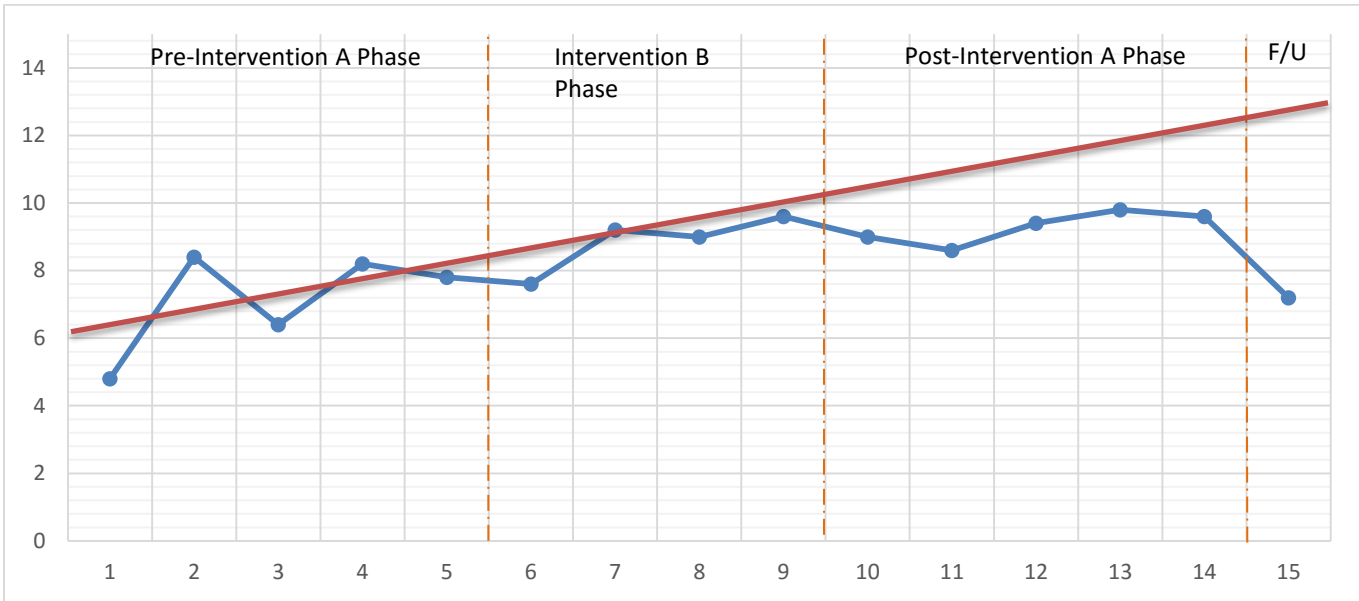
COPM Satisfaction Scores: average pre-intervention phase scores = 7.2; average intervention phase scores = 8.9; average post-intervention phase scores = 9.4; three month follow-up score = 6.0.

Figure 10 Standard Deviation Band Calculations for Participant 3 COPM Performance Scores



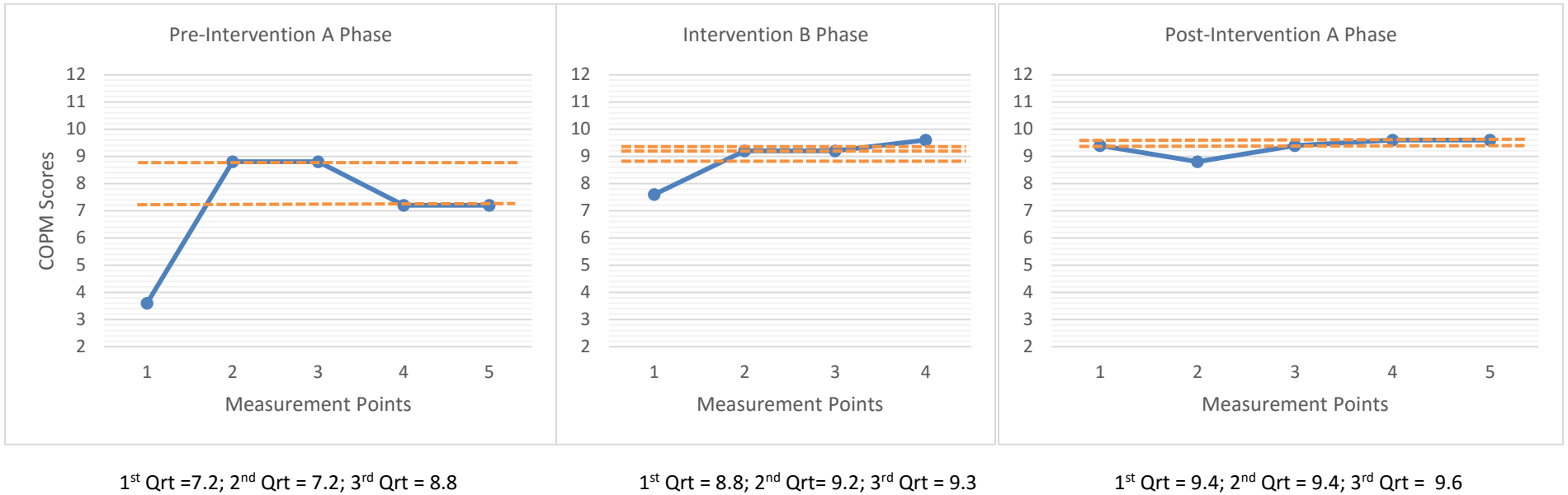
The upper and lower limits of the standard deviation bands for the pre-intervention and post-intervention phases do not overlap, suggesting that there was a statistically significant increase in COPM performance scores across phases for Participant 3.

Figure 11 Celeration Line - Split Middle Method - for Participant 3 COPM Performance Scores



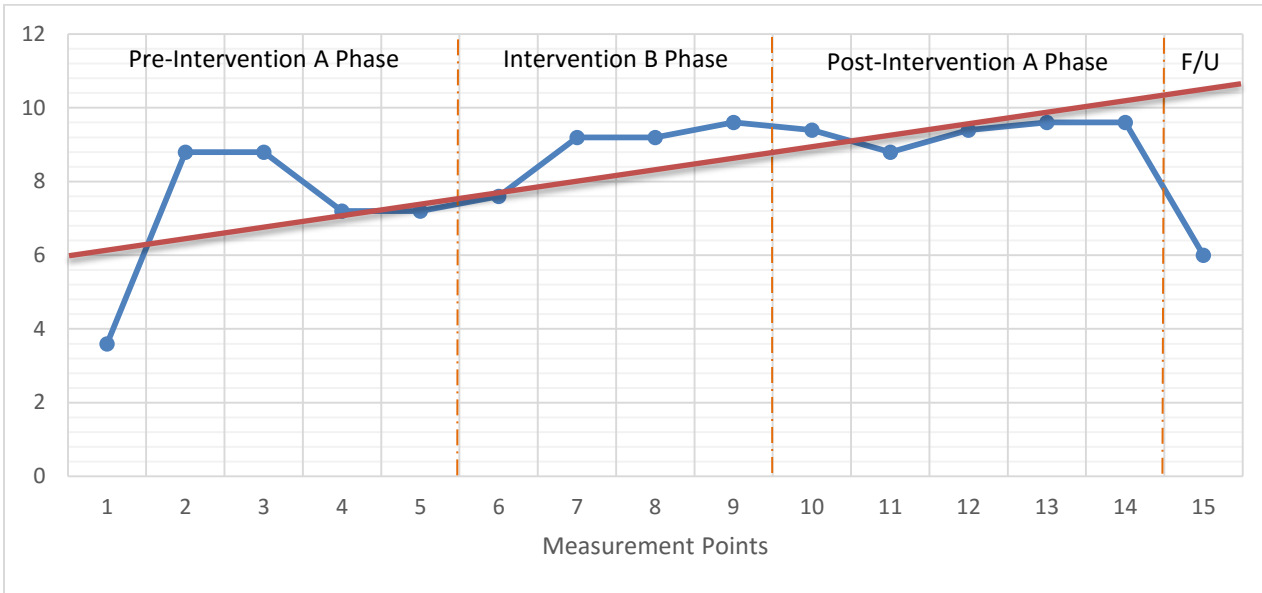
Almost all data points fell below the baseline celeration line for the intervention, post-intervention, and follow-up phases. This suggests that there was a statistically significant difference in COPM performance scores for Participant 3 in that scores were lower than expected following the pre-intervention phase; however, celeration line predicts impossible scores beyond the intervention phase, as the COPM scale does not go above 10.

Figure 12 Interquartile Band Calculations for Participant 3 COPM Satisfaction Scores



The upper and lower limits of the interquartile band ranges for each phase do not overlap, suggesting that there was a statistically significant difference in COPM satisfaction scores across phases for Participant 3.

Figure 13 Celeration Line - Split Middle Method - for Participant 3 COPM Satisfaction Scores



Data points mostly fell above the baseline celeration line in the intervention phase, but data points mostly fell below the baseline celeration line in the post-intervention and follow-up phases. This suggests a statistically significant difference in COPM satisfaction scores for Participant 3, in that scores increased more than expected during the intervention phase, then were lower than expected during the post-intervention and follow-up phases.

4.2.2 Parkinson Disease Questionnaire-39 (PDQ-39)

The PDQ-39 was completed five times in the pre-intervention *A* phase, four times in the intervention *B* phase, five times in the post-intervention *A* phase, and once at the three month follow-up with each participant with Parkinson's disease.

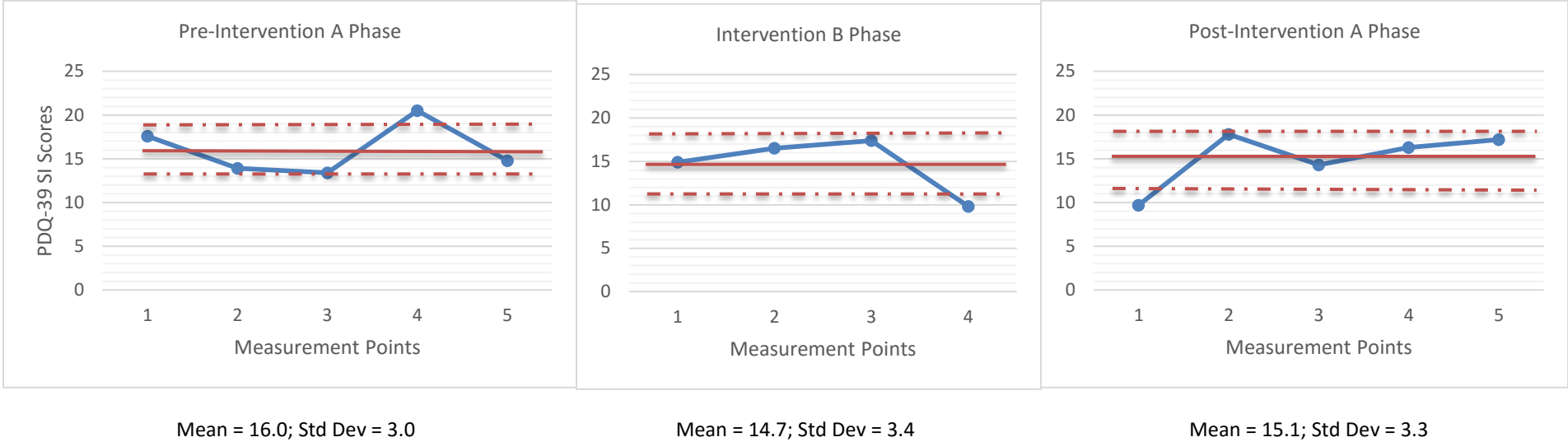
Statistical analysis found that the data collected using the PDQ-39 with Participant 1 and with Participant 3 was normally distributed in the pre-intervention, intervention, and post-intervention phases. The data collected with Participant 2 was not normally distributed in the pre-intervention phase, but was normally distributed in the intervention and post-intervention phases. On the following pages, *Tables 4.6, 4.7, and 4.8* show the PDQ-39 Summary Index scores at each measurement point for Participant 1, Participant 2, and Participant 3 respectively. Following each table are figures illustrating the standard deviation band / interquartile band calculations and acceleration line calculations for the PDQ-39 Summary Index scores from each individual participant.

Table 4.6 PDQ-39 Summary Index Scores for Participant 1

Measurement Point	Summary Index Score
Pre-A1	17.6
Pre-A2	13.9
Pre-A3	13.4
Pre-A4	20.5
Pre-A5	14.8
B1	14.9
B2	16.5
B3	17.4
B4	9.8
Post-A1	9.7
Post-A2	17.8
Post-A3	14.3
Post-A4	16.3
Post-A5	17.2
3 Month F/U	18.6

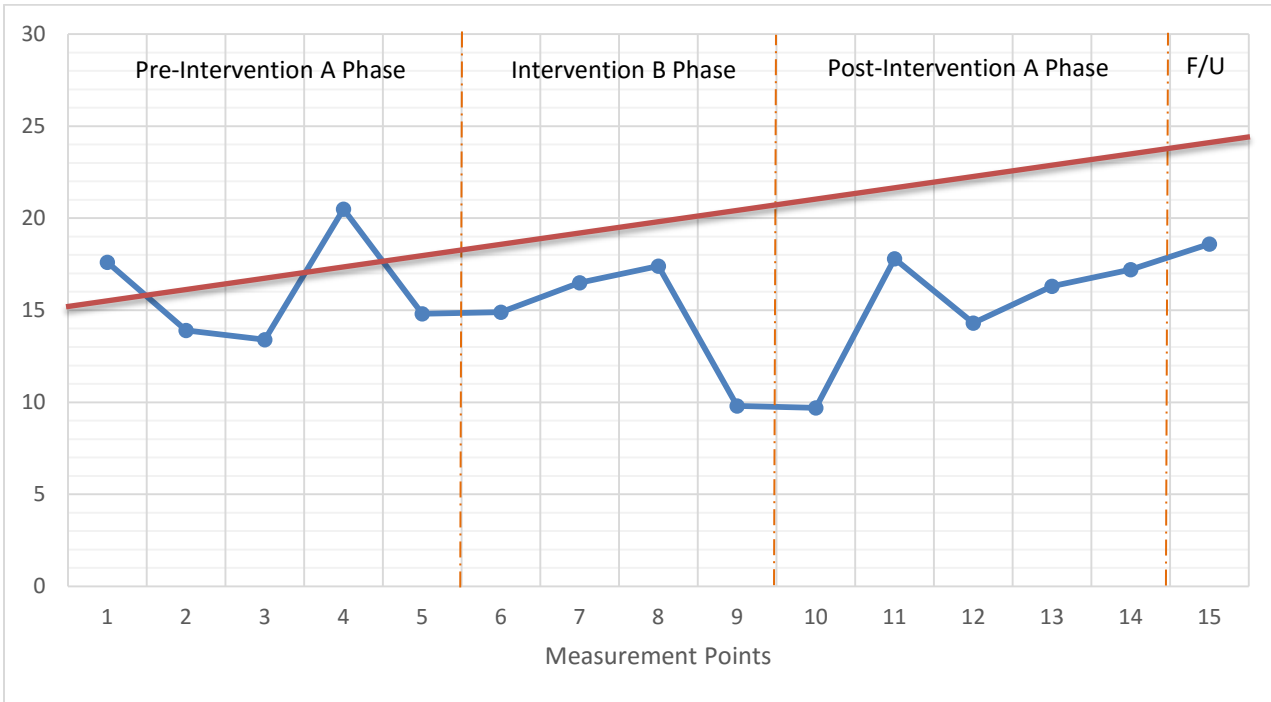
Average pre-intervention phase scores = 13.1; average intervention phase scores = 14.7; average post-intervention phase scores = 15.1; three month follow-up score = 18.6 (lower scores indicate better health-related quality of life; a change of 6 points or greater is considered clinically significant).

Figure 14 Standard Deviation Band Calculations for Participant 1 PDQ-39 Summary Index Scores



The upper and lower limits of the standard deviation bands for each phase overlap, suggesting there was not a statistically significant difference in PDQ-39 Summary Index scores across phases for Participant 1.

Figure 15 Celeration Line - Split Middle Method - for Participant 1 PDQ-39 Summary Index Scores



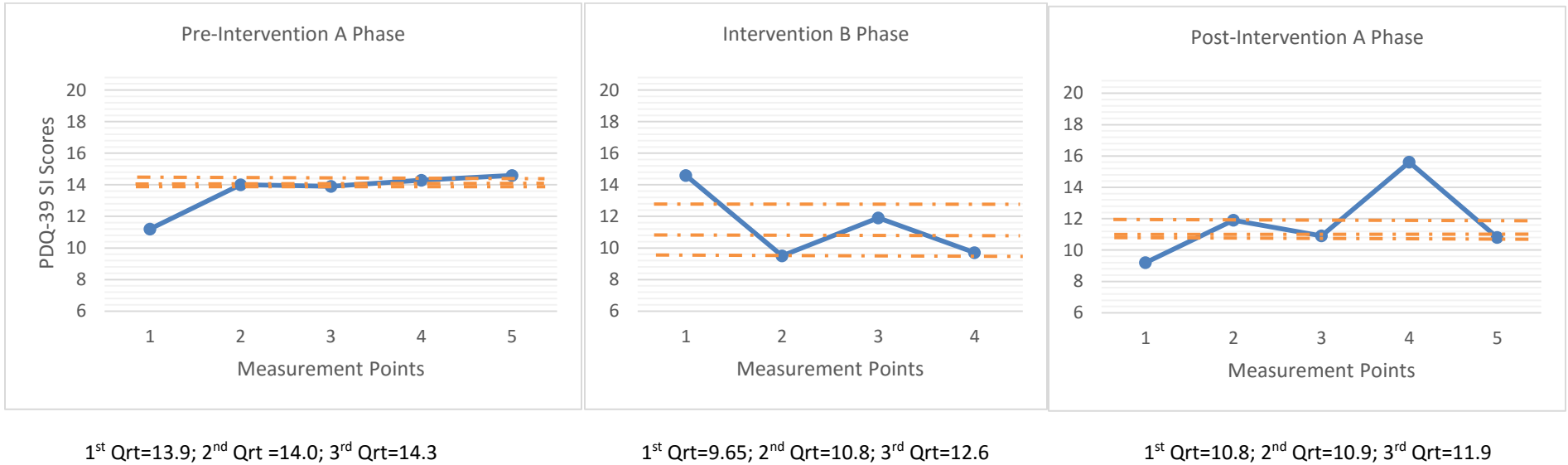
Data points fell below the baseline celeration line for the intervention, post-intervention, and follow-up phases. This suggests that there was a statistically significant decline in PDQ-39 SI scores for Participant 1 from what was expected beyond the pre-intervention phase.

Table 4.7 PDQ-39 Summary Index Scores for Participant 2

Measurement Point	Summary Index Score
Pre-A1	11.2
Pre-A2	14.0
Pre-A3	13.9
Pre-A4	14.3
Pre-A5	14.6
B1	14.6
B2	9.5
B3	11.9
B4	9.7
Post-A1	9.2
Post-A2	11.9
Post-A3	10.9
Post-A4	15.6
Post-A5	10.8
3 Month F/U	11.5

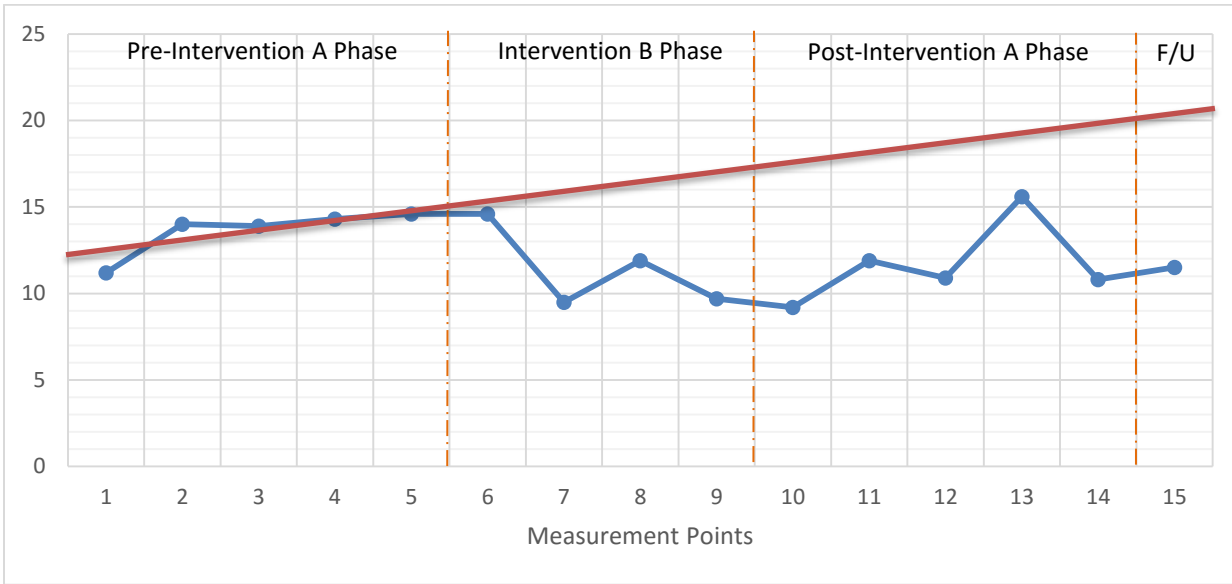
Average pre-intervention phase scores = 13.6; average intervention phase scores = 11.4; average post-intervention phase scores = 11.7; three month follow-up score = 11.5; a change of 6 points or greater is considered clinically significant.

Figure 16 Interquartile Band Calculations for Participant 2 PDQ-39 Summary Index Scores



The upper and lower limits of the interquartile bands for the pre-intervention phase do not overlap with the intervention or post-intervention phases, suggesting there was a statistically significant decline in PDQ-39 Summary Index scores across phases for Participant 2.

Figure 17 Celeration Line - Split Middle Method - for PD2 PDQ-39 Summary Index Scores



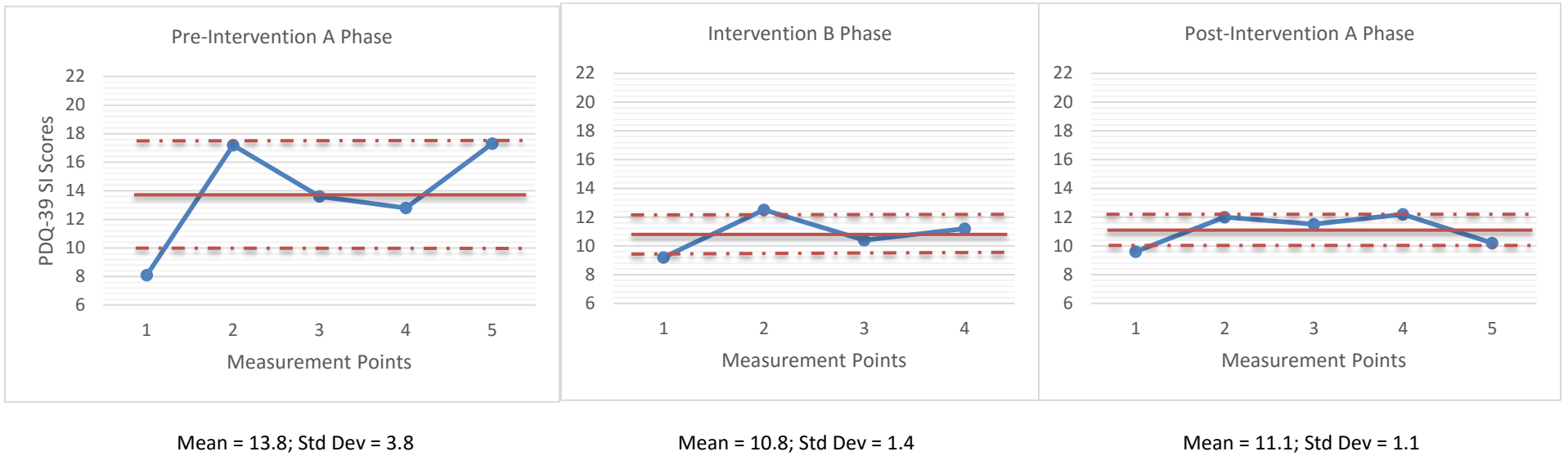
Data points fell below the baseline celeration line for the intervention, post-intervention, and follow-up phases. This suggests that there was a statistically significant decrease in PDQ-39 SI scores for Participant 2 from what was expected beyond the pre-intervention phase.

Table 4.8 PDQ-39 Summary Index Scores for Participant 3

Measurement Point	Summary Index Score
Pre-A1	8.1
Pre-A2	17.2
Pre-A3	13.6
Pre-A4	12.8
Pre-A5	17.3
B1	9.2
B2	12.5
B3	10.4
B4	11.2
Post-A1	9.6
Post-A2	12.0
Post-A3	11.5
Post-A4	12.2
Post-A5	10.2
3 Month F/U	12.8

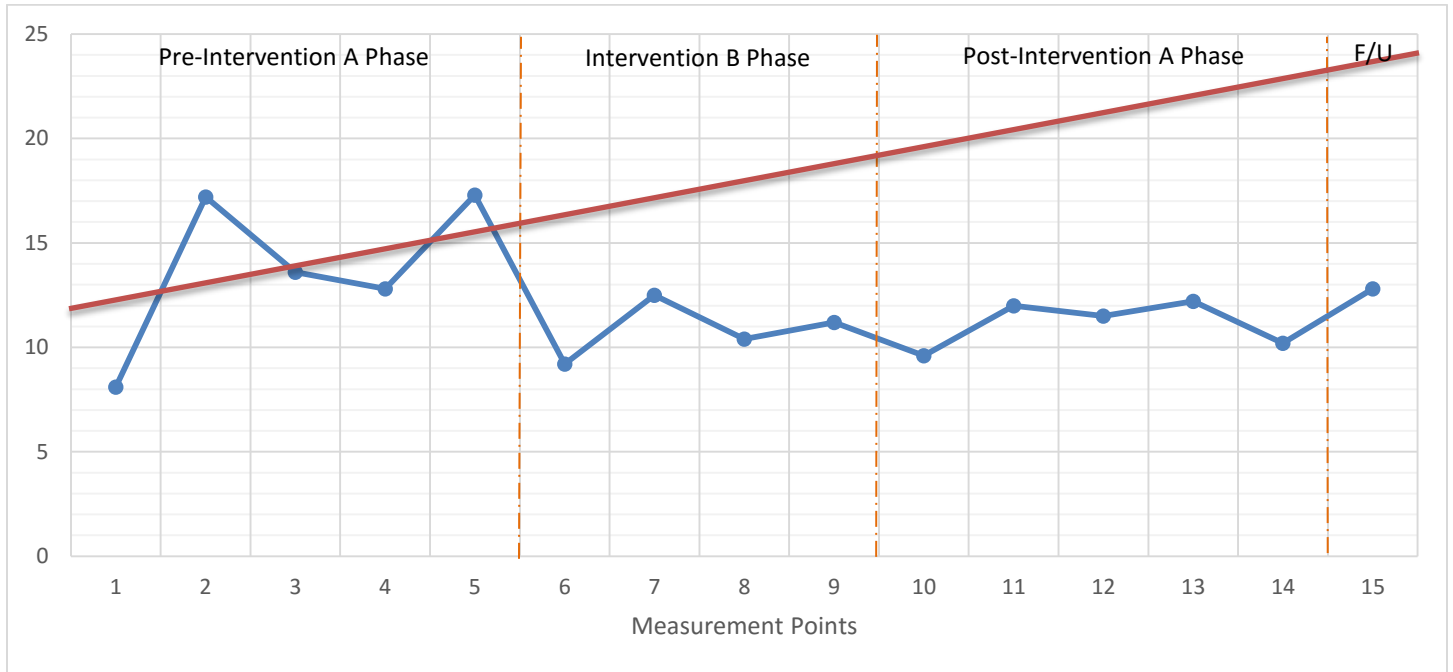
Average pre-intervention phase scores = 13.8; average intervention phase scores = 10.8; average post-intervention phase scores = 11.1; three month follow-up score = 12.8; a change of 6 points or greater is considered clinically significant.

Figure 18 Standard Deviation Band Calculations for Participant 3 PDQ-39 Summary Index Scores



The upper and lower limits of the standard deviation bands for each phase overlap, suggesting there was not a statistically significant difference in PDQ-39 Summary Index scores across phases for Participant 3.

Figure 19 Celeration Line - Split Middle Method - for Participant 3 PDQ-39 Summary Index Scores



Data points fell below the baseline celeration line in the intervention, post-intervention, and follow-up phases. This suggests that there was a statistically significant decline in PDQ-39 SI scores for Participant 3 from what was expected beyond the pre-intervention phase.

4.2.3 Zarit Burden Interview (ZBI)

The ZBI was completed five times in the pre-intervention A phase, four times in the intervention B phase, five times in the post-intervention A phase, and once at the three month follow-up with each caregiver.

Statistical analysis found that the data collected using the ZBI with Caregiver 1 was not normally distributed in the pre-intervention, intervention, or post-intervention phases. The data collected with Caregiver 2 was not normally distributed in the pre- or post-intervention phases, but was normally distributed in the intervention phase. The data collected with Caregiver 3 was

not statistically different from normal in the pre-intervention and intervention phases, but was statistically different from normal in the post-intervention phase.

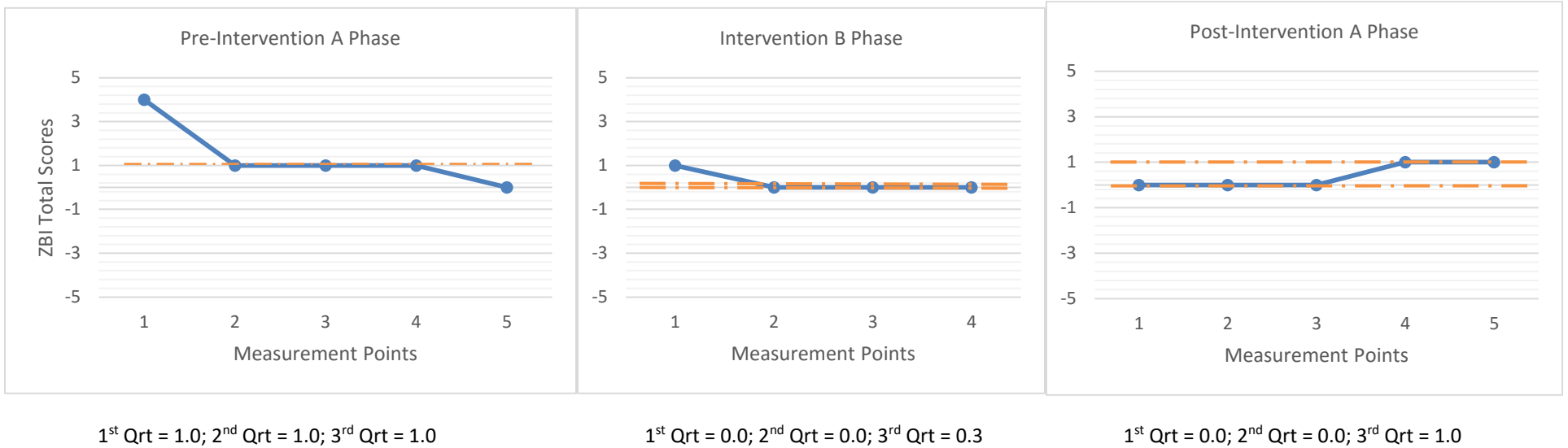
On the following pages, *Tables 4.9, 4.10, and 4.11* show the ZBI scores at each measurement point for Participant 1, Participant 2, and Participant 3, respectively. Following each table are figures illustrating the standard deviation band / interquartile band calculations and acceleration line calculations for the ZBI scores for each individual caregiver.

Table 4.9 ZBI Scores for Caregiver 1

Measurement Point	Total /88
Pre-A1	4.0
Pre-A2	1.0
Pre-A3	1.0
Pre-A4	1.0
Pre-A5	0.0
B1	1.0
B2	0.0
B3	0.0
B4	0.0
Post-A1	0.0
Post-A2	0.0
Post-A3	0.0
Post-A4	1.0
Post-A5	1.0
3 Month F/U	5.0

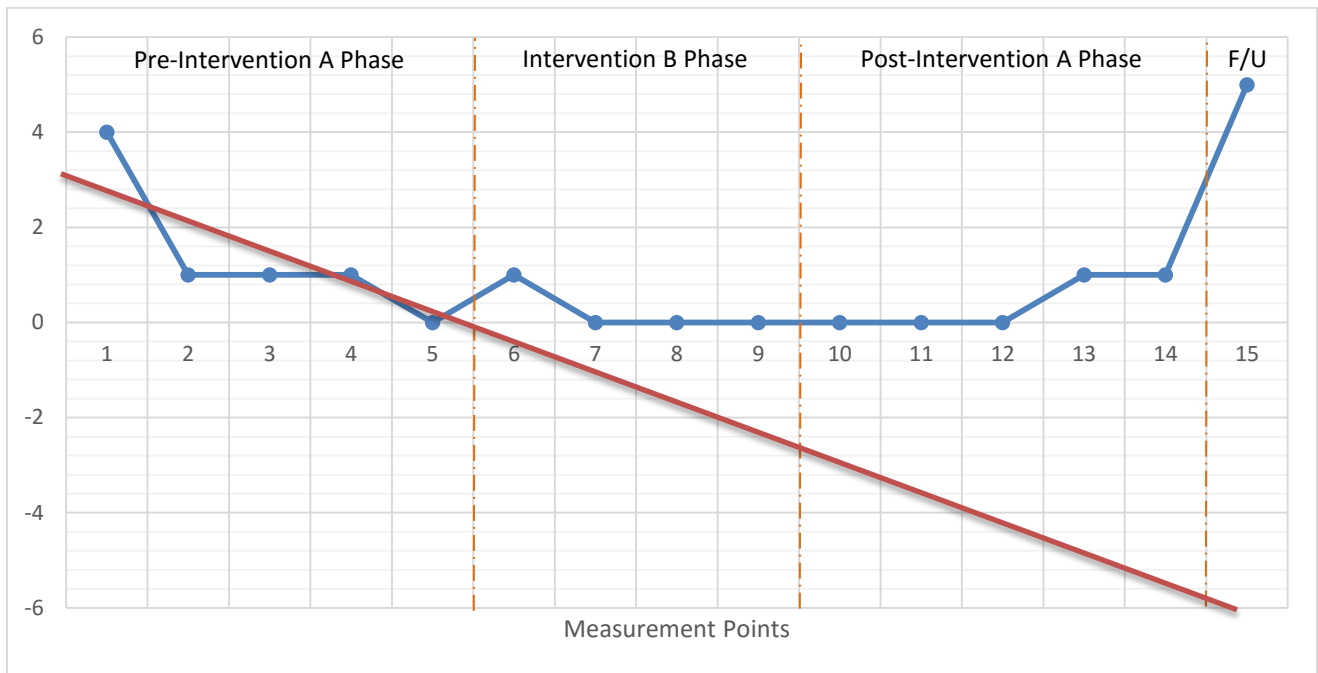
No score > 24; therefore no indication of high caregiver burden

Figure 20 Interquartile Band Calculations for Caregiver 1 ZBI Total Scores



Although the upper and lower limits of the interquartile bands between the pre-intervention and intervention phases do not overlap, the upper and lower limits of the interquartile bands of the pre-intervention and intervention phases both overlap with the interquartile band range of the post-intervention phase, suggesting there was not a statistically significant difference in ZBI scores across phases for Caregiver 1.

Figure 21 Celeration Line - Split Middle Method - for Caregiver 1 ZBI Total Scores



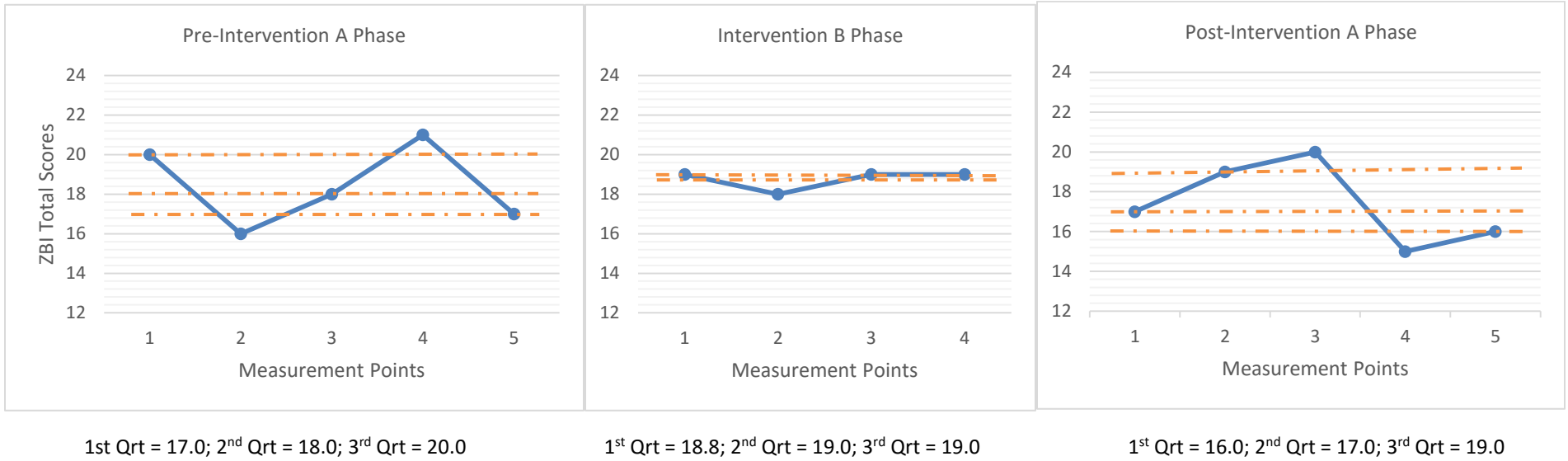
Data points appeared to fall above the baseline celeration line for the intervention, post-intervention, and follow-up phases, but since negative numbers are not possible on the ZBI and most of Caregiver 1's scores are the lowest possible on the measure, a statistically significant change in ZBI scores has not actually occurred.

Table 4.10 ZBI Scores for Caregiver 2

Measurement Point	Total /88
Pre-A1	20.0
Pre-A2	16.0
Pre-A3	18.0
Pre-A4	21.0
Pre-A5	17.0
B1	19.0
B2	18.0
B3	19.0
B4	19.0
Post-A1	17.0
Post-A2	19.0
Post-A3	20.0
Post-A4	15.0
Post-A5	16.0
3 Month F/U	17.0

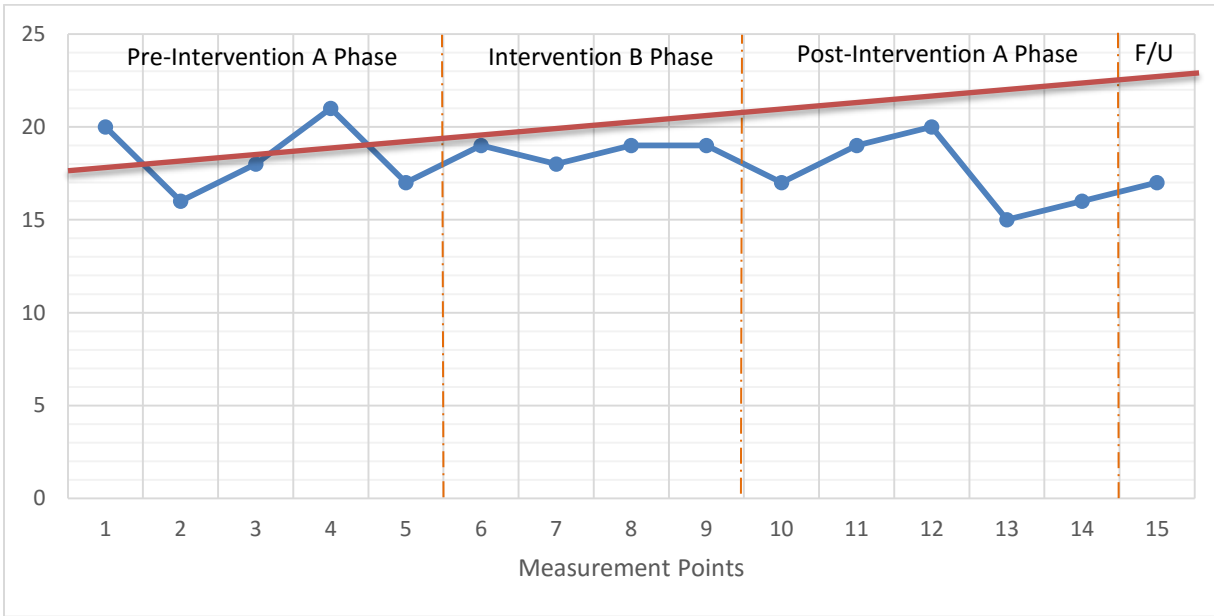
No score > 24; therefore no indication of high caregiver burden

Figure 22 Interquartile Band Calculations for Caregiver 2 ZBI Total Scores



The upper and lower limits of the interquartile bands for each phase overlap, suggesting that there was not a statistically significant difference in ZBI scores across phases for Caregiver 2.

Figure 23 Celeration Line - Split Middle Method - for Caregiver 2 ZBI Total Scores



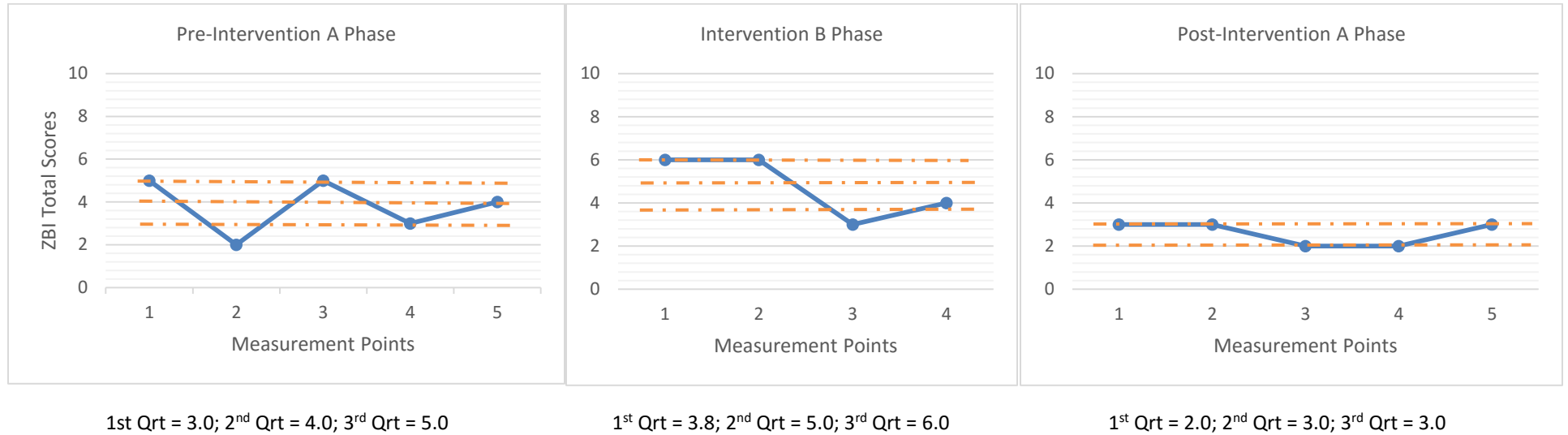
Data points fell below the baseline celeration line for the intervention, post-intervention, and follow-up phases. This suggests there was a statistically significant decrease in ZBI scores for Caregiver 2 from what was expected beyond the pre-intervention phase, although visually, the trend of the scores does not appear to have changed across phases.

Table 4.11 ZBI Scores for Caregiver 3

Measurement Point	Total /88
Pre-A1	5.0
Pre-A2	2.0
Pre-A3	5.0
Pre-A4	3.0
Pre-A5	4.0
B1	6.0
B2	6.0
B3	3.0
B4	4.0
Post-A1	3.0
Post-A2	3.0
Post-A3	2.0
Post-A4	2.0
Post-A5	3.0
3 Month F/U	9.0

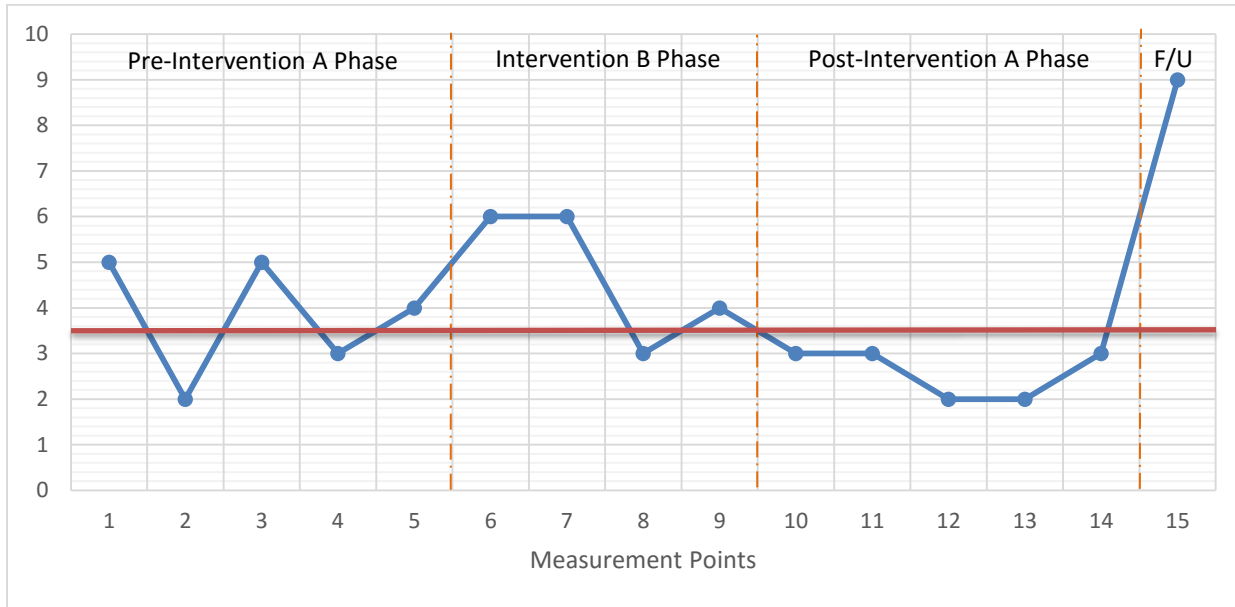
No score > 24; therefore no indication of high caregiver burden

Figure 24 Interquartile Band Calculations for Caregiver 3 ZBI Total Scores



The upper and lower limits of the interquartile bands for the post-intervention phase do not overlap with the upper and lower limits of the pre-intervention and intervention phases. This suggests there was a statistically significant decrease in ZBI scores from the pre-intervention phase to the post-intervention phase for Caregiver 3.

Figure 25 Celeration Line - Split Middle Method - for Caregiver 3 ZBI Total Scores



The data points mostly fell above the baseline celeration line in the intervention phase, but then mostly fell below the baseline celeration line in the post-intervention phase before returning above the baseline celeration line in the follow-up phase. This suggests there was a statistically significant increase in ZBI scores during the intervention phase, a statistically significant decrease in ZBI scores during the post-intervention phase, and another statistically significant increase in ZBI scores for Caregiver 3 from what was expected beyond the pre-intervention phase.

4.2.4 Summary of Quantitative Data

4.2.4.1 COPM Quantitative Data Summary

Statistical and visual analysis of COPM data found variable degrees of improvement in average COPM performance and satisfaction scores for all three participants 3 during the study period, some of which was maintained three months following treatment; however, statistical and visual analysis actually found a decrease in average COPM performance and satisfaction scores for Participant 1 by the three month follow-up.

For Participant 1, findings from statistical and visual analysis suggested there had been no significant change in average COPM performance scores between the pre-intervention and

post-intervention phases, but COPM performance scores had actually decreased between the post-intervention phase and the three month follow-up (*Figures 2 and 3*). Findings from different statistical analysis methods contradicted each other regarding average COPM satisfaction scores, in that the standard deviation band method suggested there had been no significant change in scores (*Figure 4*) but the celeration line method suggested that average COPM satisfaction scores improved during the intervention and post-intervention phases and then decreased between the post-intervention phase and the three month follow-up (*Figure 5*). Visual analysis findings were consistent with findings from the celeration line analysis method and suggested there was a clinically significant decrease in average COPM satisfaction scores from the post-intervention phase to the three month follow-up (*Figure 5*). When two statistical methods contradict each other in single subject data analysis, as is known to sometimes occur, visual analysis should be considered authoritative (Nourbaksh & Ottenbacher, 1994). On the COPM 10-point scale, there was no clinically significant change in average COPM performance scores across the study period; i.e., change in average COPM performance scores across the study period was < 2 points (*Table 4.2*). However, there was a clinically significant decrease in average COPM satisfaction scores from the post-intervention phase to the three month follow-up; i.e., there was a 2.0-point decrease in average COPM satisfaction scores from the post-intervention phase to the three month follow-up (*Table 4.2*).

For Participant 2, statistical and visual analysis suggested that average COPM performance scores improved following the pre-intervention phase and that improvements were maintained three months following treatment (*Figures 6 and 7*). Findings from statistical analysis of COPM satisfaction scores contradicted each other in that the standard deviation band method

suggested that no significant change had occurred (*Figure 8*) but the celeration line suggested that that average COPM satisfaction scores were lower than expected beyond the pre-intervention phase (*Figure 9*). Visual analysis suggested that a clinically significant improvement in COPM satisfaction scores actually took place across the study period, but that this improvement in scores actually began during the pre-intervention phase (*Figure 9*). On the COPM scale, clinically significant improvements in average COPM performance scores and average COPM satisfaction scores appeared to have taken place and improvements were maintained three months following treatment; i.e., average COPM performance scores improved by 2.0 points and average COPM satisfaction scores improved by 2.8 points from pre-intervention to three month follow-up (*Table 4.3*).

For Participant 3, statistical methods once again contradicted each other in that the standard deviation band method suggested that average COPM performance scores (*Figure 10*) and average COPM satisfaction scores (*Figure 12*) had improved, but the celeration line method suggested that average COPM performance scores (*Figure 11*) and average COPM satisfaction scores (*Figure 13*) were lower than expected following the pre-intervention phase. When considering the discrepancy between findings from the two statistical analysis methods that were used, it is important to note that Participant 3's average COPM performance scores and average COPM satisfaction scores were near the top of the COPM scale during the intervention and follow-up phases, creating a ceiling effect for both sets of scores, therefore predictions from celeration line analysis are not valid for this measure. Visual analysis findings were consistent with findings from the standard deviation band analysis method and suggested that average COPM performance scores (*Figure 11*) and average COPM satisfaction scores (*Figure 13*)

improved following the pre-intervention phase but improvements were not maintained three months following treatment. On the COPM scale, clinically significant improvements appeared to have taken place in average COPM performance scores and average COPM satisfaction scores from the pre-intervention phase to the post-intervention phase; i.e., there was a 2.2-point improvement in average COPM performance scores and also in average COPM satisfaction scores, but improvements were not maintained following treatment; i.e. average COPM performance scores and average COPM satisfaction scores three months following treatment were < 2.0 points different from pre-intervention scores (*Table 4.4*).

4.2.4.2 PDQ-39 Quantitative Data Summary

Findings from different statistical analysis methods contradicted each other regarding PDQ-39 Summary Index scores for Participant 1 and Participant 3, although visual analysis suggested that there was no clinically significant change in scores for Participant 1 but there was a clinically significant change in scores for Participant 3. Statistical and visual analysis of PDQ-39 Summary Index scores for Participant 2 suggested that scores improved (decreased) following the pre-intervention phase. Improvements in scores for Participant 2 and Participant 3 were maintained three months following treatment.

For Participant 1, statistical analysis methods contradicted each other regarding PDQ-39 Summary Index score findings, in that the standard deviation band method suggested there was not a statistically significant difference in scores across phases (*Figure 14*), but the celeration line method suggested that scores were lower than expected following the pre-intervention phase (*Figure 15*). Visual analysis findings were consistent with findings from the standard deviation band analysis method and suggested that there was no clinically significant change in PDQ-39

Summary Index scores following the pre-intervention phase (*Figure 15*). As stated earlier, when two statistical methods contradict each other in single subject data analysis, visual analysis should be considered authoritative (Nourbaksh & Ottenbacher, 1994). Therefore, in consideration of all data analysis methods as a whole, there did not appear to be a clinically significant change in PDQ-39 Summary Index scores for Participant 1.

For Participant 2, statistical and visual analysis suggested that PDQ-39 Summary Index scores improved (decreased) from the pre-intervention phase to the post-intervention phase and this improvement was maintained three months following treatment (*Figures 16 and 17*); however, scores changed by less than 6 points, suggesting that no clinically significant change had occurred.

For Participant 3, statistical analysis methods contradicted each other regarding PDQ-39 Summary Index score findings, in that the standard deviation band method suggested no statistically significant change had occurred (*Figure 18*) but the celeration line method suggested that scores had improved (decreased) following the pre-intervention phase and this improvement was maintained three months following treatment (*Figure 19*). As described earlier, statistical analysis methods with single subject data should not replace visual analysis (Nourbaksh & Ottenbacher, 1994), and findings from visual analysis of PDQ-39 Summary Index scores for Participant 3 are consistent with findings from the celeration line analysis method and suggested that scores improved (decreased) following the pre-intervention phase and that improvements were maintained three months following treatment (*Figure 19*); however, since scores changed by less than 6 points, no clinically significant change seemed to have occurred.

4.2.4.3 ZBI Quantitative Data Summary

Findings from ZBI score data analysis suggested that there was not a significant change in scores for Caregiver 1 across the study period until the three month follow up, when scores actually worsened. A very small improvement in ZBI scores was suggested for Caregiver 2, while a larger improvement in ZBI scores was suggested for Caregiver 3. Improvements in ZBI scores for Caregiver 2 were maintained three months following treatment but ZBI scores actually worsened for Caregiver 3 three months following treatment.

For Caregiver 1, the two statistical methods used to analyze ZBI scores contradicted each other, in that the standard deviation band method suggested that there was not a significant difference in scores across the study period (*Figure 20*) but the celeration line method suggested that scores were higher than expected following the pre-intervention phase (*Figure 21*). Despite this contradiction, results from the standard deviation band method should be accepted over results from the celeration line method because expected results from the celeration line method would not be logical: since Caregiver 1 scored “0” on the ZBI throughout most of the intervention and post-intervention phases, scores predicted by the celeration line are negative numbers that are impossible on the ZBI scale. Visual analysis findings were consistent with standard deviation band analysis findings and suggested that no clinically significant change in ZBI scores had occurred during the study period, although visual analysis also suggested that ZBI scores had worsened (increased) three months following treatment (*Figure 21*). ZBI scores did not indicate high caregiver stress for Caregiver 1 at any time during the study period.

For Caregiver 2, the two statistical methods used to analyze ZBI scores contradicted each other, in that the interquartile band method suggested that there was no change in ZBI scores

across phases (*Figure 22*) but the celeration line method suggested that ZBI scores improved (decreased) following the pre-intervention phase and this change was maintained three months following treatment (*Figure 23*). As discussed earlier, statistical analysis should not replace visual analysis; visual analysis findings concurred with findings from the celeration line method and suggested that ZBI scores improved following the intervention phase, although this improvement was very small, and the improvement was maintained three months following treatment (*Figure 23*). ZBI scores did not indicate high caregiver stress for Caregiver 2 at any time during the study period.

For Caregiver 3, statistical and visual analysis suggested that scores improved (decreased) following the pre-intervention phase, but later worsened (increased) from the post-intervention phase to the three month follow-up (*Figures 24 and 25*). Despite fluctuations in scores, ZBI scores were not high enough to indicate high caregiver stress for Caregiver 3 at any time during the study period.

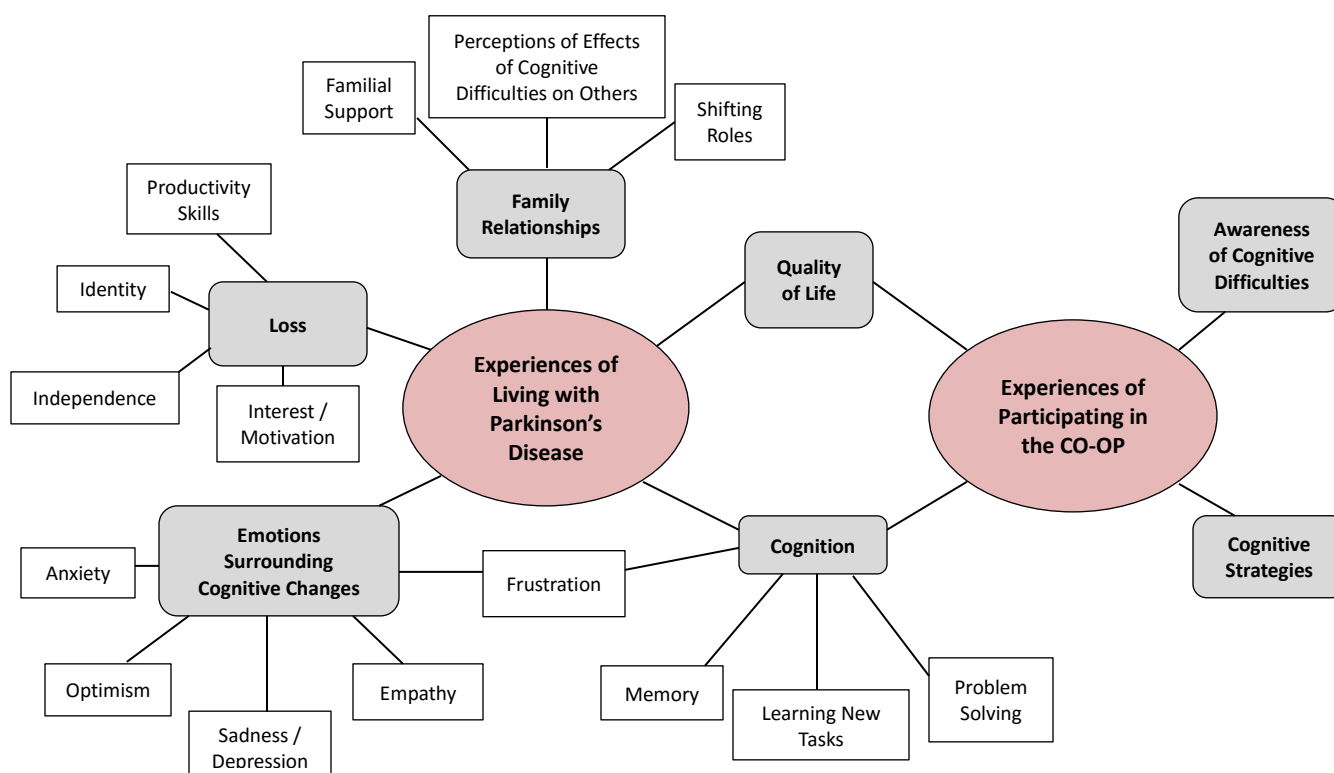
4.3 Qualitative Data

Responses from the participants with Parkinson's disease and from their caregivers during the one-on-one semi-structured interview sessions that were completed pre-intervention, mid-intervention, post-intervention, and three months following the end of the intervention can be summarized into two major themes: "experiences of living with Parkinson's disease," and "experiences of participating in the CO-OP." Experiences of living with Parkinson's disease had no relation to the timing of treatment sessions, as participation in the CO-OP had no direct influence on Parkinson's disease symptoms themselves, nor was it expected to. Due to the degenerative nature of Parkinson's disease, any changes in experiences of living with

Parkinson's disease over the study period were attributable to the progressive nature of the disease process itself. The theme of experiences of participating in the CO-OP, however, was directly related to the timing of treatment sessions, independently of disease progression.

Within the theme of experiences of living with Parkinson's disease, the following categories emerged: cognition (with sub-categories of memory, ability to learn new tasks, and problem solving skills), loss (loss of skills related to productivity, loss of identity, loss of independence, loss of interest and motivation), emotions surrounding cognitive changes (anxiety, awareness/empathy of the effect of participants' cognitive difficulty on others, optimism, sadness/depression), quality of life, and family relationships, (familial support, self-perceived effects of participants' cognitive difficulties on their family members, and shifting roles). Within the theme of experiences of participating in the CO-OP, the category of cognition also appeared (with sub-categories of memory, ability to learn new tasks, problem solving, frustration with cognitive difficulties), as well as the following categories: awareness of cognitive limitations, cognitive strategies, and quality of life. The following diagram illustrates a thematic map showing both qualitative themes of "experiences of living with Parkinson's disease" and "experiences of participating in the CO-OP" as well as each category and subcategory that was identified during qualitative data analysis.

Figure 26 Thematic Map of Qualitative Data Analysis



Interview content and quotes have been sorted according to the two major themes of “experiences of living with Parkinson’s disease” and “experiences of participating in the CO-OP” and then further organized into categories and sub-categories. To show the changes that took place in participants’ and caregivers’ thoughts and feelings in regard to each sub-category over time, content and quotes have been organized chronologically within each sub-category, starting with content from the pre-intervention interviews, then progressing through content from the mid-intervention, post-intervention, and three-month follow-up interviews when appropriate. In the interest of maintaining clarity, content from interviews with all three participants has been

grouped together separately from content from interviews with all three caregivers. Following the descriptions of comments within the themes of “experiences of living with Parkinson’s disease” and “experiences of participating in the CO-OP,” comments from the participants and caregivers regarding constructive criticism of the delivery of the CO-OP program are described.

4.3.1 Theme One: Experiences of Living with Parkinson’s Disease

As stated in the introduction of this thesis, Parkinson’s disease is a progressive neurodegenerative condition (Nussbaum & Ellis, 2003), and cognitive impairment is a common non-motor symptom of Parkinson’s (Moberg, 2007). As a progressive disease, it is expected that an individual diagnosed with Parkinson’s disease-related cognitive impairment may notice deterioration in their cognitive abilities over time. Close family members are even more likely to notice cognitive deterioration in an individual with Parkinson’s disease, since Parkinson’s-related cognitive impairment itself may reduce an individual’s insight into his or her own cognitive limitations. Study participants and their caregivers discussed their thoughts and feelings in regard to many aspects of cognitive deterioration that were part of their experiences of living with Parkinson’s disease.

4.3.1.1 Cognition

At each interview session with the participants, they shared their perceptions about their own cognitive strengths and limitations in the areas of memory (short- and long-term memory, memory for names, and memory for familiar routes when driving), ability to learn how to do new tasks, and problem solving skills. Caregivers also shared their perceptions about the cognitive strengths and limitations they felt they had observed in their spouses. Many of the comments from the participants and caregivers reflected on perceptions that the participants’ cognition had

declined over the passage of time, independent of any possible effects of the CO-OP treatment intervention, but instead followed the typical experience of deterioration that is well known to be a common characteristic of Parkinson's disease (Emre, Aarsland, & Brown, 2007; Moberg, 2007; York & Alvarez, 2008).

All three participants described that they felt that their long term memories were personal strengths, but all also felt they had difficulty with short term memory, and that this difficulty affected their ability to perform meaningful activities such as remembering familiar routes when driving, and remembering words and names during conversation. For example, Participant 1 described, *"Like, in the city, when I go to different streets, I don't have the ability to know where they are and I used to know where they are so I could travel there with no problems at all."* Participant 1 and Participant 3 mentioned that they didn't used to have such problems with their memories (i.e., remembering familiar routes when driving) in the past, and Participant 1 and Participant 2 both stated that they felt that their memory had worsened further by the end of the study period.

Two of the caregivers agreed with the participants' descriptions of their memory difficulties, while one caregiver did not. Although Caregiver 1 stated that she felt that Participant 1 had difficulty remembering names, differently from Participant 1, she attributed his difficulty to the natural course of aging, and felt that Participant 1 blamed his Parkinson's symptoms too often for problems that she felt were minor and were unrelated to his diagnosis. Caregivers 2 and 3 both felt more strongly than Caregiver 1 that their respective spouses had difficulty with memory and both attributed their spouses' difficulty to Parkinson's disease. Caregiver 3 described her husband's memory difficulties this way: *"He's notorious for not putting things*

back where they belong...he'll put something back in the most obscure place...and he says, just the other day, it was 'Don't we have a broom?' ...he couldn't even remember whether we had a broom or not at one point." Caregiver 2 stated that she felt that Participant 2's mental processing speed was slow when he attempted to recall information. Similar to the descriptions given by the participants, Caregivers 1 and 2 both expressed that they felt that their spouses' long-term memory was better than their short-term memory, and Caregiver 1 and Caregiver 3 felt that their spouses' memory difficulties had worsened by the end of the study period.

Regarding the participants' abilities to solve problems, two of the three caregivers felt that their spouses' problem solving skills had deteriorated since they had developed Parkinson's disease, while the other caregiver felt there had been no change in her spouse's problem solving skills. Caregiver 1 did not feel at any point that Participant 1 had any significant difficulties with analyzing or finding solutions to problems in day to day life, whereas Caregiver 2 felt that Participant 2 had difficulties with solving problems in that he was slower, was more dependent on family members to help him, and he tended to avoid dealing with unexpected events more often than he had been prior to developing Parkinson's. Similar to Caregiver 1, Caregiver 3 also felt that her spouse did not have any significant difficulties with problem solving, but similar to Caregiver 2, Caregiver 3 felt that Participant 3 was slower with problem solving than he used to be. None of the caregivers felt that their respective spouses' problem solving skills had changed while participating in the treatment program or following treatment.

4.3.1.2 Loss

At each of their interviews, the participants expressed feelings of loss related to the changes they have experienced in their thinking abilities over the duration of their experiences

with Parkinson's disease. Their perceptions of loss included the loss of skills related to productivity, the loss of identity/roles, the loss of communication skills, the loss of independence, and the loss of interest and motivation in regard to previously enjoyed activities. Caregivers also commented on their own observations of losses they felt their spouses had gone through since being diagnosed with Parkinson's disease. From the perspectives of the participants and the caregivers, the losses they each described were attributable to the progression of Parkinson's disease and were not affected by participation in the CO-OP.

All three participants described losses that they had experienced of their skills related to productive activities since they had been diagnosed with Parkinson's disease, although of the caregivers, only Caregiver 2 described that she felt that Participant 2 had lost skills and interest in activities related to his past work since he was diagnosed with Parkinson's. Participants 1 and 2 both also expressed feelings of loss of their identities and previous roles since developing Parkinson's disease, and commented on losses of leadership roles in particular: Participant 1 within his family and Participant 2 within his workplace. For example, Participant 1 said, *"I'm not the same father and I'm not the same husband and I'm not the same neighbour as I used to be."* Caregiver 1 and Caregiver 2 also commented on changes they felt had occurred in regard to shifting roles between their respective spouses and themselves, largely in the direction of increased dependence of their spouses and increased responsibilities for the caregivers. In regard to feelings of loss of communication skills, both Participant 1 and Participant 2 felt that this loss was related to new problems with their memory for words and also to new problems remembering what others have said in conversation since developing Parkinson's; Participant 2 expressed embarrassment in relation to this loss. Of the three caregivers, only Caregiver 2

commented that she felt that her spouse had lost communication skills since his diagnosis of Parkinson's disease. Specifically, Caregiver 2 described that Participant 2 had developed difficulty following conversation, difficulty participating in a group, and had lost fluency in two of the three languages he used to speak very well. In regard to feelings of loss of independence, Participant 2 and Participant 3 both expressed feelings of loss of independence and increased reliance on others to assist them with day to day activities such as remembering to take medications on time since they began experiencing Parkinson's symptoms. Caregiver 2 and Caregiver 3 also both commented that they felt that their respective spouses had lost some of their independence and were relying more on the caregivers for help with day to day activities as their Parkinson's disease had progressed; Caregiver 2 wondered aloud if Participant 2 may have become overly dependent on her. In regard to feelings of loss of motivation, Participant 1 stated that he had lost motivation to participate in activities he was previously interested in prior to developing Parkinson's symptoms. Participant 3 also expressed a lack of motivation to find solutions to difficulties he was having with day to day activities, such as remembering to take his medications on time, but differently from Participant 1, he did not seem particularly bothered by his lack of motivation. For example, Participant 3 said, *"I often thought if I'd get some kind of wrist watch that would buzz (for medication times), but I couldn't find one so I gave up on it."* Caregiver 2 commented that she felt that Participant 2 was less motivated to get involved in activities than he used to be prior to developing Parkinson's disease, and had less interest in things related to the work he used to do, although Participant 2 himself did not comment that he had lost any motivation to remain involved in activities that used to interest him.

As described on the previous page, all three participants commented on feelings of loss in regard to many aspects of their daily lives that had changed since they had begun experiencing Parkinson's symptoms. Comments from participants about loss focused primarily on loss of skills related to productivity, loss of communication skills, loss of independence, loss of previous roles, and loss of motivation. Comments from caregivers about loss were largely consistent with comments from participants, although Caregiver 1 did not comment about loss at any point.

4.3.1.3 Emotions

Participants expressed a variety of emotions related to their perceptions of their own cognitive limitations at their interviews. These emotions included feelings of frustration, anxiety/worry, empathy related to the effect of their cognitive difficulties on others, and sadness/depression. Caregivers expressed their own observations of emotions they felt that their spouses experienced, as well as observations of changes in self-confidence that they had observed in their spouses. Caregivers also described their own emotions related to their perceptions of their spouses' cognitive limitations. Since one participant's expressions of frustration changed along with changes in his awareness of his own cognitive limitations during his participation in the CO-OP program (while whether another participant's feelings of frustration changed during the study period is unknown), details of the participants' feelings of frustration will be described later under the 'changes in awareness of cognitive limitations' category in the 'experiences of participating in the CO-OP' theme section. Since the caregivers' perceptions of their spouses' frustration as well as the caregivers' feelings of their own frustration did not change during the study period and seemed more directly related to the caregivers' experiences living with a spouse with Parkinson's disease, details of the caregivers'

perceptions regarding frustration will be described in this section. All other emotions expressed by participants and caregivers seemed to be related only to their experiences with Parkinson's disease rather than their experiences of participating in the CO-OP, and are therefore described in this category. The two caregivers who commented on the participants' self-confidence had conflicting opinions regarding whether or not the CO-OP had any effect on self-confidence, but for simplicity, both those comments are described under the 'experiences with participating in the CO-OP' theme.

Both Caregiver 2 and Caregiver 3 stated that they felt that their respective spouses felt frustrated with the cognitive difficulties that they had developed after they began experiencing Parkinson's symptoms. Caregiver 3 also stated that she felt that Participant 3's frustration had not changed since he had begun participating in the CO-OP program, however, she also felt that Participant 3's frustration did not prevent him from doing things he wanted to do. Caregiver 1 and Caregiver 3 also expressed their own frustrations about different aspects of their spouses' behaviour. For example, Caregiver 1 expressed frustration at Participant 1's feelings that his cognitive limitations were entirely due to his Parkinson's disease, whereas she disagreed. Caregiver 3's expression of frustration was more directly related to her feelings about Participant 3's cognitive limitations and how she copes with her frustration. She said, *"I do get frustrated at times, but I just bite my tongue and...move on."*

Participants 1 and 3 commented on feelings of anxiety / worry related to their thinking difficulties in different ways. Participant 1 expressed feelings of anxiety surrounding the changes he had experienced in his cognition since he was diagnosed with Parkinson's disease and how those changes may worsen in the future. He described his feelings this way: *"my biggest fear is that I may become dependent on someone."* Participant 1's anxiety appeared to worsen over

time, and he said at a later interview, *"I'm definitely feeling more stressed...I pray every day that it won't get worse."* Participant 3 did not discuss any thoughts about the future when he discussed his feelings of anxiety. Caregiver 1 expressed feelings of anxiety related to Participant 1's difficulties with his thinking, but she also stated that she didn't mention her worries to her husband.

Participant 1 and Participant 3 both expressed awareness, empathy, and concern in regard to how their thinking difficulties may affect their wives. For example, Participant 3 said, *"she (his wife) gets frustrated with me at times. I can't blame her for that."*

Participants 2 and 3 both expressed optimism in regard to their thinking abilities during the study period. For example, when asked how his difficulties with his thinking made him feel about himself and his abilities, Participant 2 stated: *"I was always called an optimist, you know?...I think that's still there...life is still beautiful."* Participant 3 also expressed optimism this way: *"I realize I'm slowing down, but I think my abilities are still very strong."*

Participant 1 expressed feelings of sadness and possibly depression when asked how his difficulties with his thinking made him feel about himself and his abilities. He described his feelings this way: *"I often or sometimes think that I am getting older, I just had a birthday as you know, and at some point, I'd rather go to heaven than to stay here."*

Caregiver 2 commented on her perceptions about things that she feels make Participant 2 sad in relation to the difficulties he has experienced with his thinking. She said, *"there are two things that make him sad...I think a few years ago he was much more interested in his past work with (company) because he grew with that organization and he would look so forward to current details of what was happening, but that is not as important."* No caregivers made any comments in regard to any perceptions of sadness they may have felt that their spouses were experiencing,

although Caregiver 1 stated that Participant 1 was happier since he had participated in the treatment program, and that their daughter agreed that Participant 1 seemed happier.

Although none of the participants themselves made any comments regarding their feelings of self-confidence, Caregiver 1 and Caregiver 2 both commented about changes they had seen in their spouses' self-confidence in relation to their spouses' difficulties with their thinking abilities. Caregiver 1 felt that Participant 1's self-confidence had improved since he participated in the treatment program. Caregiver 2, on the other hand, expressed that, in general, Participant 2's self-confidence continued to be not as good as it used to be prior to developing Parkinson's disease.

4.3.1.4 Quality of Life

Participants expressed a variety of self-perceived effects of their difficulties with their thinking on their quality of life, as well as self-perceived changes in their quality of life over the course of participating in the CO-OP treatment program. Caregivers also expressed a variety of feelings in regard to the effects that their spouses' difficulties with their thinking had on the caregivers' quality of life. Since many of the participants' comments regarding quality of life were related to their experiences of participating in the CO-OP, those comments are described in the "quality of life" category under the "experiences of participating in the CO-OP" theme section. Since the caregivers' all commented that their own quality of life had not changed during the study period, their comments were considered to represent their experiences of living with a spouse with Parkinson's disease and are described in this section.

Each caregiver made different comments in regard to how their spouses' difficulties with their thinking had affected the caregivers' quality of life since the participants had been

diagnosed with Parkinson's disease. For example, Caregiver 1 felt that the differences of opinion between Participant 1 and herself in regard to the severity and cause of his thinking difficulties created some conflict in their relationship. Caregiver 2 felt that communication between Participant 2 and herself had been negatively affected by his slower response to questions in conversation. Caregiver 3, on the other hand, felt that Participant 3's thinking difficulties had no effect on her quality of life other than to make her feel frustrated at times. Despite their earlier comments, at post-intervention, all three caregivers stated that they felt that their spouses' thinking difficulties had no effect on the caregivers' quality of life.

4.3.1.5 Family relationships

In their interviews, participants made comments in regard to their perceptions of the support they receive from their families for their cognitive difficulties as well as the effects of their cognitive difficulties on their family members. The participants' perceptions of support from their families did not change during the study period. With the exception of conflicting comments from Participant 1, the comments from the participants regarding the effects of their cognitive difficulties on their family members also did not change during the study period. Caregivers' comments in regard to family relationships focused mainly on shifting roles of household responsibilities from the participants with Parkinson's to the caregivers, and were discussed earlier in the category of loss of identity/roles so they will not be duplicated here, although it is worth noting that, similar to the comments from the participants regarding family relationships, the caregivers' comments in regard to family relationships also did not describe any change during the study period.

Both Participant 1 and Participant 2 commented on the support and encouragement that they received from their wives and adult children in regard to their cognitive difficulties. For example, Participant 2 described that he and his wife write things down in a calendar that they consult together daily. Participant 1 commented that he felt that his family was helpful and treated him well, but he suspected that his family discussed him and his limitations when he wasn't around.

Participant 1 initially described that he felt that his difficulties with his thinking did not affect his wife much and that the two of them had a good relationship. Later at his mid-intervention interview, Participant 1 stated that he felt that his difficulties with his thinking were likely having negative effects on his wife and other family members, and also expressed empathy for his family members, but at his post-intervention interview, Participant 1 contradicted himself again and said that he did not feel that his thinking difficulties affected his wife. Differently from Participant 1, Participant 2 and Participant 3 both consistently expressed feelings that their difficulties with their thinking affected their wives negatively, and also expressed empathy for how these negative effects may have made their wives feel. For example, Participant 3 said, "*she (his wife) gets frustrated with me at times. I can't blame her for that.*"

4.3.2 Theme Two: Experiences of Participating in the CO-OP

Participants and their caregivers described a variety of experiences related to participating in the CO-OP treatment program. The participants perceived many more effects of the CO-OP on their cognition than the caregivers felt they had observed. The participants' comments of the effects of the CO-OP on different aspects of their cognition (memory, ability to learn new tasks, and problem solving skills) will be discussed below, whereas the caregivers'

comments regarding cognition were discussed earlier under the “experiences with living with Parkinson’s disease” theme. Many comments were made by the participants and caregivers regarding the increased awareness that both the participants and the caregivers gained regarding the participants’ cognitive difficulties while participating in the CO-OP program and ways in which this increased awareness was beneficial. Participants and caregivers also commented on cognitive strategies that the participants used to help manage difficulties with their thinking and how the use of strategies changed over the study period.

4.3.2.1 Cognition

At the mid-intervention, post-intervention, and three-month follow-up interviews, the participants discussed their perceptions of how the CO-OP treatment program may have impacted their cognitive abilities, the changes they experienced in their awareness of their cognitive limitations during the treatment program, and cognitive strategies that they use to improve their success with completing tasks that they find cognitively difficult. In some instances, participants and their respective caregivers did not agree on whether or not the CO-OP treatment had much effect on the participants’ cognition; these differences of opinion will be highlighted.

4.3.2.1.1 Memory

Only Participant 3 felt that the CO-OP program had helped to improve his memory. He stated at his mid-intervention interview that he felt that this improvement had occurred because the treatment program had improved his awareness of the limitations of his memory and what steps to take to reach his memory-related goal. Participant 3 commented again at his post-

intervention interview that he was remembering things better than he had been able to prior to participating in the CO-OP. At his three month follow-up interview, Participant 3 felt that, although he still had problems with his memory, he was still benefiting from a memory compensation strategy that he had discovered for himself during the treatment program: *“I get a little late sometimes (with his medication schedule), but I’m getting better because this watch (a strategy he implemented himself during the CO-OP program) has helped me out.”*

4.3.2.1.2 Ability to Learn New Tasks

When discussing their abilities to learn new tasks, participants’ opinions about their abilities varied between each other as well as across time. Participants 1 and 2 both felt that they had difficulties with learning new tasks, but that these difficulties became easier due to the strategies they had learned in the CO-OP treatment program. Participant 3 did not feel at any point that he had difficulty learning new tasks, and so he logically did not feel that the treatment program had any effect on this ability. By the three month follow-up interviews, all three participants felt that they had no difficulties with learning new tasks.

At their pre-intervention interviews, participants had differing opinions of their own abilities to learn how to do new things. Participants 1 and 2 both felt that they have difficulty learning new tasks, while Participant 3 did not feel that learning new tasks was a problem for him. Participant 1 described it this way: *“anything that I have to learn new is troublesome.”*

At the mid-intervention interviews, only Participant 1 stated that he felt that he had difficulty learning to do new things, although both Participant 1 and Participant 3 said that their ability to learn new things had changed since they began participating in the CO-OP. Despite still

feeling that he had difficulty learning to do new things, Participant 1 felt that his approach to new tasks was now different, and that his new approach incorporated the steps of the global strategy he learned in CO-OP. Participant 3 said that he felt that his ability to learn new tasks had changed because the CO-OP program was helping him to become more aware of his abilities. Participant 2 did not feel that his ability to learn new tasks has changed since he began participating in the CO-OP program.

At their post-intervention interviews, Participants 1 and 3 both felt that they did not have much difficulty learning new tasks. Participant 2, on the other hand, felt that he had substantially more difficulty with learning new tasks. Participant 1 attributed his confidence in his ability to learn new things to his awareness of tools he can use to reach his goals, although it was not clear if the tools he was referring to were tools he had been using prior to participating in the CO-OP, if the tools were the strategies he had learned in the CO-OP program, or both. Participants 1 and 2 both felt that, since participating in the CO-OP treatment program, they were now better able to organize and prepare themselves to approach new tasks. Participant 3 felt that his ability to learn new tasks had not changed since he participated in the CO-OP; however, he had stated earlier in this interview and all previous ones that he did not feel he had difficulty learning new tasks anyway.

At their three months follow up interviews, all three participants stated that they did not have any particular difficulty learning new tasks. Participant 1 felt that his ability to learn new tasks had changed a bit since he had participated in the CO-OP, but he did not elaborate on his response. Neither of the other two participants felt that their ability to learn new tasks had changed since they had participated in the CO-OP.

Differently from the opinions of the three participants, all three caregivers felt that their respective spouses were slower with learning new tasks by the end of the study period than they had been prior to developing Parkinson's disease, and that the CO-OP had no effect on this difficulty. Caregiver 2 described that she felt that Participant 2 had become hesitant when faced with learning new tasks, whereas he hadn't been hesitant before his Parkinson's diagnosis, and had begun avoiding learning new tasks altogether; however, Caregiver 2 also commented that she felt that the CO-OP global strategy had provided a structure for Participant 2's approach to learning new tasks. For example, Caregiver 2 said, *"It doesn't seem so much like a stumbling block...you know, planning, carry out, and the check."*

4.3.2.1.3 Problem Solving Skills

Each participant had differing opinions regarding their own problem solving skills, how those skills changed during the study period, and whether or not participating in the CO-OP had affected their problem solving skills.

At their pre-intervention interviews, Participants 1 and 3 both stated that they felt they had little or no difficulty with problem solving, whereas Participant 2 felt that his mental processing time for problem solving was slower than it used to be prior to developing Parkinson's disease.

At their mid-intervention interviews, Participant 3 continued to feel that he didn't have much difficulty with problem solving, and Participant 2 continued to feel that it took longer for him to solve problems than it used to prior to having Parkinson's disease. Neither Participant 2 nor Participant 3 felt that their abilities to analyze and find solutions to problems in day-to-day

life had changed since they had begun participating in the CO-OP program. On the other hand, Participant 1 felt that since beginning participation in the CO-OP treatment program, he had gained some direction in regard to how to approach problems and found this information helpful.

At their post-intervention interviews, Participant 1 stated that he felt that he actually had more difficulty with problem solving than he did prior to participating in the CO-OP program, whereas Participants 2 and 3 did not feel that they had much difficulty with problem solving. Participants 1 and 2 both stated that they felt that the CO-OP program had helped them to learn to think differently about problem solving, and Participant 3 felt that his memory in regard to problem solving had improved since he had participated in the CO-OP.

At their three month follow-up interviews, all three participants stated that they felt that their difficulties with problem solving were minimal. Participant 1 and Participant 3 both stated that they felt that participating in the CO-OP treatment had changed how they approach problems. For example Participant 3 said, *“I pay attention to where I’m driving more than I used to...I’m starting to get back in the habit of watching road signs...I maybe not work as fast as I used to, I’m slowing down, so I’m taking more time to analyze.”* Participant 2 did not feel that his problem solving skills had changed since he had participated in the CO-OP treatment program.

Similar to the differences of opinion between the participants and caregivers regarding whether or not the CO-OP had any effect on the participants’ ability to learn new tasks, none of the caregivers felt that the CO-OP had any effect on the problem solving skills of any of the participants. Descriptions of the caregivers’ comments regarding the participants’ problem solving skills were provided earlier under the ‘experiences of living with Parkinson’s disease’ theme.

4.3.2.1.4 Frustration with Cognitive Difficulties

Two participants commented on feelings of frustration with their cognitive difficulties during their interviews. At his pre-intervention interview, Participant 1 expressed frustration with his cognitive difficulties several times, but did not discuss feelings of frustration at any of his later interviews. It is therefore unknown if Participant 1's feelings of frustration changed during the study period. At the mid-intervention and post-intervention interviews, only Participant 3 expressed frustration with his cognitive difficulties. At the mid-intervention interview, Participant 3 felt that his frustration had gotten worse since he began participating in the CO-OP because he had become more aware of his cognitive difficulties, but at his post-intervention interview he stated that he felt that his frustration may have improved a little since he began participating in the CO-OP treatment program due to insight he had gained about how to manage his difficulties more effectively. When asked at his post-intervention interview if his feelings of frustration had changed since he participated in the treatment program, Participant 3 said, "*A little bit, yeah...I try to take my time and do the task at hand...realizing I can't rush or you can't do it as fast as I used to be able to.*" No comments were made by any participants in regard to feelings of frustration with their cognitive difficulties at the three-month follow-up interviews.

4.3.2.2 Awareness of Cognitive Difficulties

All three participants commented at various points during the study period that they felt that participating in the CO-OP had helped to improve their awareness of their cognitive difficulties. All three participants also commented that they felt that the caregivers' awareness of the participants' cognitive difficulties had increased as well. The participants felt that the caregivers' improved awareness had increased the caregivers' empathy toward the participants.

Two of the caregivers agreed that their spouses' awareness of their own cognitive difficulties had improved since they began participating in the CO-OP. These two caregivers stated that they felt that their awareness of their spouses' cognitive difficulties had also improved, which helped the caregivers to cope better with the thinking difficulties their spouses were experiencing and to support their spouses better.

At his mid-intervention interview, Participant 3 commented several times that his awareness of his cognitive difficulties had increased since he began participating in the CO-OP treatment program. As stated previously, Participant 3 felt that his increased awareness of his cognitive difficulties had helped to improve his memory and had also improved his ability to learn new tasks. He also felt, however, that his increased awareness had also increased his frustration with his cognitive difficulties. At their post-intervention interviews, Both Participant 2 and Participant 3 commented that they felt that their awareness of their cognitive difficulties had increased since they participated in the treatment program. Participant 2 elaborated on this topic and said that the CO-OP program had helped to improve his awareness of his memory difficulties and helped him to compensate for these difficulties by re-organizing his thinking. In his words, Participant 2 stated that the CO-OP helped him to "*prepare better.*" At the three-month follow-up interviews, only Participant 2 stated again that the CO-OP treatment program had increased his awareness of his cognitive limitations.

At their mid- and post-intervention interviews, Participant 2 and Participant 3 both stated that they felt that participation in the CO-OP program had improved their wives' understanding and tolerance of the participants' difficulties with their thinking. At the three month follow-up

interviews, Participant 3 continued to say that he felt that his wife was more understanding of his difficulties with his thinking, as did Participant 1.

At their mid-intervention interviews, both Caregiver 2 and Caregiver 3 concurred with their respective spouses' statements that they (Participant 2 and Participant 3) had become more aware of their own cognitive difficulties since they began participating in the treatment program. At her post-intervention interview, Caregiver 2 again concurred with Participant 2's statements that he had become more aware of his cognitive difficulties since he participated in the treatment program. At her three month follow-up interview, Caregiver 2 expressed a different perspective than she had at her mid-intervention and post-intervention interviews, and stated that she felt that Participant 2 was not very aware of his cognitive decline. Caregiver 3 did not comment in regard to Participant 3's awareness of his cognitive difficulties at either the post-intervention or 3 month follow-up interviews. Caregiver 1 did not comment in regard to Participant 1's awareness of his cognitive difficulties in any of her interviews throughout the study period.

At their mid-intervention and three month follow-up interviews, Caregiver 2 and Caregiver 3 both felt that the CO-OP treatment program had been helping to improve their own awareness of their spouses' thinking difficulties, and that this increased awareness was helping the caregivers to cope better with these difficulties. For example, at mid-intervention, Caregiver 3 said, *"I'm more aware...that it is Parkinson's that's doing it (causing Participant 3's difficulties with his thinking), and so I just take it as it comes now, for the most part."* At her three month follow-up interview, Caregiver 2 described how she had adapted her own behaviour in response to her new awareness of her husband's cognitive difficulties, and described it this way: *"if he asks me something and a while later he asks me, I'll just say it again, maybe a little slower."*

Caregiver 1 did not comment in regard to her own awareness of Participant 1's cognitive difficulties in any of her interviews throughout the study period.

4.3.2.3 Cognitive Strategies

Prior to participating in the CO-OP, none of the participants were able to describe cognitive strategies that they used to help themselves manage cognitive challenges in day-to-day activities more easily, although two caregivers described cognitive strategies that they felt that their spouses used. Immediately following treatment, all three participants were able to describe the cognitive global strategy that they had learned in the CO-OP and all three stated that they found the global strategy helpful to structure their thinking. All three caregivers described a gradual increase they had noticed across time in the use of the CO-OP global strategy by the participants from the beginning to the end of treatment. At three months following treatment, all three participants were still able to describe how they could use the CO-OP global strategy but only one participant was still using it on a regular basis. Comments from the caregivers confirmed that only one participant was continuing to use the CO-OP global strategy three months following treatment.

At his mid-intervention interview, Participant 1 was able to describe a strategy he used to help improve his memory for words: *"the step I usually use now is if I can remember more than one part of it, I can recall the second part."* By mid-intervention, neither Participant 2 nor Participant 3 were able to describe any cognitive strategies that they used, and none of the three participants spontaneously described how they could use the global strategy from the CO-OP.

At their post-intervention interviews, Participant 1 and Participant 3 both described strategies they used to help improve their success with completing cognitively demanding tasks. For example, Participant 3 described the following strategy that he learned from participating in the CO-OP: *“I try to take my time and do the task at hand...realizing I can't rush.”*

At their three-month follow-up interviews, all three participants discussed cognitive strategies that they had used or could use to organize their thinking in order to complete tasks with cognitive demands. All three participants were still able to describe how they would or did use the CO-OP global strategy to achieve a goal. Despite the familiarity all three participants still seemed to have with the CO-OP global strategy, only Participant 2 had continued to use the CO-OP global strategy on his own following the end of the treatment program to work toward achieving goals that he set for himself: he showed and described 12 new CO-OP goal sheets he had developed and worked on independently over the 3 months since the end of the treatment program, as well as the 5 goal sheets he had worked on during the treatment program and has continued to use. Although he was no longer using the CO-OP to work toward accomplishing new goals, Participant 3 felt that he was still benefiting from a memory compensation strategy that he had discovered for himself during the treatment program: *“I get a little late sometimes (with his medication schedule), but I'm getting better because this watch (a strategy he implemented himself during the CO-OP program) has helped me out.”*

At their pre-intervention interviews, both Caregiver 1 and Caregiver 2 stated that their respective spouses utilized strategies to manage their difficulties with their thinking, whereas Caregiver 3 stated that Participant 3 did not utilize any strategies. The strategies described by

Caregivers 1 and 2 included such things as practice, using a calendar, asking for help, relying on spouse for reminders, and avoidance.

At their mid-intervention interviews, both Caregiver 1 and Caregiver 2 felt that their respective spouses had begun to use the CO-OP global strategy to manage their difficulties with their thinking since they began participating in the treatment program, whereas Caregiver 3 did not feel that Participant 3 was using the strategy outside of doing his homework. Caregiver 2 stated that Participant 2 uses another strategy to help his concentration when reading, and said, *“depending on the level of difficulty of something he’s (Participant 2) reading, he will lip the reading...it slows down, and it helps to think about it.”*

At their post-intervention interviews, all three caregivers stated that their spouses had been using the CO-OP global strategy to help manage their difficulties with their thinking since they participated in the treatment program, but at their three month follow-up interviews, the caregivers had varied responses in regard to whether their spouses were still using the CO-OP global strategy. Caregiver 1 felt that Participant 1 might still be using the CO-OP global strategy, but not every day, while Caregiver 3 stated that Participant 3 only used the global strategy if she guided him to use it. Caregiver 3 did not feel that there had been any change in how Participant 3 managed his difficulties with his thinking since he had participated in the treatment program; however, she herself found the strategy helpful to use to coach him through tasks. Caregiver 2, on the other hand, stated that Participant 2 was still using the CO-OP global strategy regularly and thought that it was helpful for him.

4.3.2.4 Quality of Life

As stated in section 4.2.1.4, participants expressed a variety of effects they felt that their difficulties with their thinking had on their quality of life, as well changes they felt had taken place in their quality of life over the course of participating in the CO-OP treatment program.

At their mid-intervention interviews, each participant had a different perspective of the effect of their difficulties with their thinking on their quality of life and how these difficulties have or have not changed since they began participating in the treatment program. Participant 1 felt that there had been a small improvement to his quality of life since beginning the CO-OP program. Participant 2 did not feel that his difficulties with his thinking affect his quality of life much, but he also felt that his quality of life had improved since he began participating in the CO-OP treatment program. Participant 3 also did not feel that his difficulties with his thinking have much effect on his quality of life, but felt that his participation in the treatment program had been helping to increase his awareness.

At his post-intervention interview Participant 1 wasn't sure if his difficulties with his thinking had much effect on his quality of life, but he did feel that what he had learned from the CO-OP program was helpful for his quality of life because the program had changed how he approaches problems. Participant 2 expressed more certainty that his quality of life had not been affected by his difficulties with his thinking, but gave conflicting responses as to whether participating in the CO-OP program was beneficial for his quality of life. Participant 3 did not feel that his difficulties with his thinking had much effect on his quality of life.

At his three-month follow-up interview, Participant 1 stated that he felt that his difficulty with his thinking had affected his life quite a bit, but also stated that he felt that participating in

the CO-OP program had helped his quality of life in some ways. Participant 2 did not feel that his difficulties with his thinking affected his quality of life much and that participating in the CO-OP had no effect on his quality of life. Participant 3 felt that participating in the CO-OP program helped improve his quality of life by teaching him how to structure his thinking differently, specifically by slowing down and thinking things through when approaching a problem.

4.3.3 Constructive Criticism

Participants and caregivers made comments in some of their interviews in regard to limitations of the treatment program or ways they felt that the treatment program could be improved.

At their three month follow-up interviews, both Participant 1 and Participant 3 commented in regard to what they felt they had not gained from the treatment program or what they thought could be improved. Participant 1 felt that his Parkinson's symptoms limited how much he could benefit from the treatment program. When asked if he had gained what he hoped for from participating in the CO-OP program, Participant 1 said, "*No, probably not...I don't think it's because of the program, I think it's because of the health condition.*" Participant 3 said that he had had no particular expectations of the treatment program, but he felt that he did not receive enough detailed information prior to the start of treatment in order for him to have a good understanding of what was going to be involved with participating in the treatment program.

At her post-intervention interview, Caregiver 3 felt that the instruction for all the CO-OP homework to be handwritten had been very difficult for Participant 3, to the point that she had

been tempted to write his homework for him while he dictated, but she did not actually do this. At her three-month follow-up interview, Caregiver 2 felt that the study could be improved if the follow-up period was longer.

4.3.4 Summary of Qualitative Data

As described above, two major themes of “experiences of living with Parkinson’s disease” and “experiences of participating in the CO-OP” emerged from interpretive description data analysis of interview transcripts from participants and caregivers. Within the theme of “experiences of living with Parkinson’s disease,” many comments were made by participants and caregivers that described how Parkinson’s disease had caused participants’ cognitive abilities to deteriorate over time. Comments were also made by participants and caregivers in regard to losses and emotions related to deteriorating cognitive abilities, quality of life, and changes in family relationships that had occurred since the participants had developed Parkinson’s. Within the theme of “experiences of participating in the CO-OP,” participants and caregivers described how the CO-OP had affected participants’ cognitive abilities. They also described an increase in awareness that all of the participants and most of the caregivers had developed of participants’ cognitive limitations and how this increased awareness had affected their lives, and also described changes in the participants’ use of cognitive strategies while participating in the CO-OP.

4.4 Findings from Observation Records and Reflective Journal Logs

4.4.1 Participant 1 and Caregiver 1

At their pre-intervention interview sessions, both Participant 1 and Caregiver 1 were talkative, friendly, and appeared to be motivated to participate in the study. Caregiver 1 appeared to be nervous, and said so, but she also expressed a desire to participate in order to help her husband. Participant 1 was able to identify five treatment goals fairly easily using the COPM. Both Participant 1 and Caregiver 1 tended to go on tangents unrelated to what had been asked of them when answering interview questions.

Throughout the treatment sessions, Participant 1 seemed to have a strong work ethic and was willing to persist in putting forth a good effort in order to do as well as he could to follow through with everything that was asked of him, including his homework. Caregiver 1 was generally encouraging to Participant 1, although she occasionally teased him when he experienced difficulty. Participant 1 and Caregiver 1 arrived on time or early to each treatment session and appeared very motivated to participate throughout the treatment program. Participant 1 remembered to bring his homework binder to every session, with homework always completed. During some of Participant 1's early treatment sessions, he tended to perseverate on information that was irrelevant to his goals and therefore tended to sabotage his ability to reach his goals; his tendency to perseverate on irrelevant information improved in later treatment sessions with guidance from the therapist. In Participant 1's early sessions, he had difficulty verbalizing the global strategy in his own words, and became quite confused in regard to the definitions of the "Do" and "Check" steps and how he should be using them. In the first three treatment sessions, the therapist gave explanations and hints in order to guide Participant 1 to a

better understanding of how to use the global strategy to reach his treatment goals. The therapist worried that she may not be adhering well to the CO-OP protocol due to her unfamiliarity with its treatment approach, and was concerned that Participant 1 may not benefit from the CO-OP treatment program as much as subsequent participants may benefit, since the therapist thought she would likely gain more familiarity and skill with administering the CO-OP program with repeated experience. After discussion with an expert and certified trainer for the CO-OP protocol, the therapist learned that the use of overt guidance and hints was a failure of adherence to the protocol (A. Hunt, personal communication, April 2014). The therapist modified her treatment approach, but continued to find it quite difficult to avoid offering hints and guidance to help Participant 1 to reach his treatment goals. Once the therapist became more comfortable with adhering to the CO-OP protocol properly, the therapist learned that the majority of the work for any participant going through the CO-OP program is to cycle multiple times through the “Plan-Do-Check” steps. The therapist also learned from Participant 1’s confusion regarding the “Do” step of the global strategy that it is imperative for the participant to actually carry out their plans so that the participant can learn for himself or herself if his or her plan worked or not. Throughout the remaining five treatment sessions, Participant 1 did follow through with his plans, sometimes during the treatment sessions themselves, and sometimes on his own at his home, and eventually developed a very good understanding of each step of the global strategy. By his eighth treatment session, Participant 1 had reached all three of the goals he had chosen to work on during treatment as well as his two untrained goals.

At the post-intervention interviews, Participant 1 and Caregiver 1 appeared much more relaxed than they had been at their pre-intervention interviews, and confirmed that they felt more

relaxed. In general, Participant 1 and Caregiver had positive feelings about having participated in the treatment program. From the therapist's perspective, Participant 1 had done very well during the treatment program, and Caregiver 1 agreed, but Participant 1 felt less sure of himself and his accomplishments. Based on observations the therapist / principal investigator had made throughout Participant 1's participation in the CO-OP study, the therapist did not believe that Participant 1's tendency to minimize his accomplishments was related to how well the treatment sessions had gone. Rather, Participant 1's comments seemed more directly related to his tendency to second guess himself in general and to see himself as less than perfect, or less than he once was.

4.4.2 Participant 2 and Caregiver 2

Throughout all interview and treatment sessions, Participant 2 and Caregiver 2 appeared to be highly motivated to participate in the study. They were on time or early to each session, and Participant 2 always remembered to bring his homework binder with him, with his homework always completed. They were both soft-spoken, although for Participant 2, his quiet speech may have been symptomatic of his Parkinson's disease. Caregiver 2 was more articulate in her responses to questions than Participant 2, but both had no difficulty keeping their responses relevant to the questions that were asked of them. Participant 2 had some difficulty identifying five treatment goals using the COPM, but was eventually able to identify five goals with suggestions from the principal investigator / therapist based on answers he and Caregiver 2 had given earlier in regard to specific activities he was having difficulties with that related to his difficulties with his thinking. The therapist had learned from the experiences of having facilitated the CO-OP program for Participant 1 previously, and was careful to clearly instruct Participant 2

not to complete the “Do” or “Check” sections of his goal sheets before he had actually followed through with acting on his plans. Participant 2 caught on to the global strategy rather quickly in the first session, which may be in part because, according to Participant 2 and Caregiver 2, the CO-OP global strategy is similar to how he used to approach tasks when he used to run a large business, but may also be because the therapist was able to provide the instructions for how to use the global strategy more clearly for Participant 2 than for Participant 1. The therapist had less difficulty adhering to the CO-OP protocol during the sessions with Participant 2 than during the previous sessions with Participant 1; however, the therapist did have difficulty remaining neutral in her comments when Participant 2’s plans to approach his goals sounded like good ones.

Unlike Participant 1, some of the goals that Participant 2 chose to work on could not be easily done in the clinical setting and were better suited to being worked on in Participant 2’s home.

When treatment sessions were held in Participant 2’s home, the therapist noted that Participant 2 seemed to feel anxious with both his wife and the therapist looking over his shoulder while he carried out his plans. When asked about his feelings, Participant 2 stated that he would feel more comfortable carrying out his plans on his own as homework and then reporting back to the therapist at the next treatment session. From observations made while providing the CO-OP program for Participant 1 and Participant 2, the therapist had noted that, while a one hour treatment session (standard for the CO-OP protocol) seemed to be long enough to review homework and discuss plans to work on for one or two goals, time generally did not permit for completing much of the “Do” or “Check” portion of the global strategy during the session. Since Participant 2 felt that he would have less anxiety if he were to carry out the “Do” portion of the global strategy on his own, and since time generally did not permit for much work on either the “Do” or the “Check” steps of the global strategy during treatment sessions anyway, the therapist

determined that it was in Participant 2's best interest to structure the remainder of the CO-OP treatment sessions so that the "Plan" step of the global strategy was completed during the treatment session, and then the "Do" and "Check" steps were assigned as homework to be reviewed at the following session. This altered structure worked well for Participant 2 throughout the remainder of his treatment sessions. He achieved all three of the goals he had chosen to work on during treatment as well as both of his untrained goals by the end of eight treatment sessions. The therapist mentioned to Participant 2 that she was impressed by how hard he had been working on his homework; Participant 2 and Caregiver 2 responded that he was choosing to spend about two hours every day on his CO-OP homework, which included developing and following through with additional goal sheets beyond focusing only on the five goals set during treatment. By the end of Participant 2's participation in the CO-OP treatment program, the therapist felt that her skill level with delivering the CO-OP program had improved in comparison to her delivery of the CO-OP program with Participant 1. Participant 2 and Caregiver 2 confirmed the therapist's thoughts by stating that they felt that the delivery of the treatment program was well organized and that all expectations were clear. Although the therapist did not outwardly feel as though there was any difference in the effort she put forth when providing the CO-OP program to Participant 2 as compared to the other participants, the therapist found Participant 2 and Caregiver 2 particularly easy to talk with and to relate to, which may have led to an unconsciously stronger commitment in the therapist to help ensure that Participant 2 did well with the treatment program compared to the other participants.

4.4.3 Participant 3 and Caregiver 3

Participant 3 and Caregiver 3 were pleasant throughout their participation in the treatment program, but they were both much less talkative than the other participants and caregivers had been. In general, their responses to all interview questions were quite short, and both Participant 3 and Caregiver 3 only expanded on their responses if prompted by further questions. Similar to the previous participant / caregiver pairs, Participant 3 and Caregiver 3 were always on time or early to each treatment session. Participant 3 also always remembered to bring his homework binder with him, with his homework completed. During his pre-intervention interview, Participant 3 had quite a lot of difficulty coming up with a total of five treatment goals using the COPM, even with suggestions from the therapist. Ultimately, the therapist decided to bring Caregiver 3 into the interview room to help Participant 3 develop enough treatment goals, and this strategy proved effective. As the therapist had done when working with Participant 2, the therapist was careful to give clear instructions to Participant 3 on the importance of not completing the “Do” or “Check” sections of his goal sheets until after he had actually carried out the “Plan” step of the global strategy. This technique seemed effective, as Participant 3 appeared to gain a good understanding of the four steps of the global strategy almost as quickly as Participant 2, and with none of the confusion that had occurred for Participant 1. Since the sessions provided to Participant 3 were the third time that the therapist had administered the CO-OP treatment program, the therapist found it much easier to adhere to the CO-OP protocol by avoiding giving any hints or guidance to Participant 3 as he was developing his plans to reach his goals. Despite the therapist’s increased confidence with administering the treatment program, the therapist continued to have difficulty avoiding making encouraging comments when Participant

3's plans sounded like good ones. Participant 3 was not able to be independent with using the global strategy as quickly and easily as Participant 2, and needed guidance during one session when he was truly "stuck" and was unable to come up with any plan at all to reach one of his treatment goals. The therapist later realized upon reflection that Participant 3's difficulty with coming up with his own plan was even more reason to avoid giving him too much help, and that instead, Participant 3 should be guided with questions about his own reasoning in order to facilitate strengthening of Participant 3's own ability to follow the global strategy on his own. The therapist made adjustments to her treatment approach for the remaining treatment sessions, and was better able to adhere to the CO-OP protocol. These adjustments seemed to be effective, since Participant 3 gradually improved in his ability to complete each step of the global strategy on his own: he became much better at independent problem solving and at thinking of more creative, effect plans that he could use to reach his treatment goals. By his seventh treatment session, Participant 3 had achieved all three of the goals he had chosen to work on during treatment, as well as his two untrained goals. Although he seemed to do very well in the treatment program, the therapist was unsure if Participant 3 found the CO-OP global strategy useful enough to continue using on his own after treatment, since, when asked, Participant 3 was unable to think of how he could continue using the global strategy once he was done participating in the treatment program.

5.0 DISCUSSION

Cognitive impairment is a very common non-motor symptom of Parkinson's disease (Moberg, 2007). Even for individuals with mild cognitive impairment, such impairments are known to negatively affect quality of life for people with Parkinson's disease and their caregivers (McKinlay, Grace, Dalrymple-Alford, & Roger, 2010; Paris, et al., 2011; Sammer, Reuter, Hullmann, Kaps, & Vaitl, 2006; Sinforiani, Banchieri, Zucchella, Pacchetti, & Sandrini, 2004), and cognitive deterioration in Parkinson's disease correlates with increased caregiver stress (McKinlay, Grace, Dalrymple-Alford, Anderson, Fink, & Roger, 2008). Impairments in executive functions in particular can limit participation in desired occupations such as socialization, instrumental activities of daily living, productive work, and leisure activities, even if motor symptoms are well-controlled by medications (Foster & Hershey, 2011), and thus can also impact negatively on patient-perceived health-related quality of life satisfaction (Eriksson, Kottorp, Borg, & Tham, 2009).

Several studies in the literature demonstrate the association between cognitive status and occupational performance in Parkinson's disease and point to the need for individualized cognitive treatment programs, in realistic environments, to encourage translation of training to improve occupational performance in both basic and instrumental activities of daily living (Disbrow, Russo, Higginson, Yund, Ventura, & Zhang, 2012; Foster & Hershey, 2011; Koerts, van Beilen, Tucha, & Brouwer, 2011; Pyun, Yang, Lee, & Yook, 2009; Rosenthal, et al., 2010). To date, only two studies published on cognitive rehabilitation in Parkinson's disease (Paris, et al., 2011; & Peña, et al., 2014) have attempted to objectively measure the relationship between improved cognition from a cognitive therapy program and function in everyday occupations.

This study aimed to examine the potential of the Cognitive Orientation to daily Occupational Performance (CO-OP) as an effective treatment tool to improve performance in daily occupations for individuals with Parkinson's related cognitive impairment.

5.1 Case Summaries

All three study participants were Caucasian men diagnosed with idiopathic Parkinson's disease and were followed regularly by movement disorder neurologists at a movement disorder clinic. All three caregivers were Caucasian women who were the wives of the participants. All participants and caregivers lived in the city of Winnipeg, Manitoba.

5.1.1 Case 1: Participant 1 and Caregiver 1

Screening measures suggested that prior to beginning treatment, Participant 1 had mild cognitive impairment, was experiencing motor symptoms of Parkinson's disease on both sides of his body but still had intact balance, was completely independent with activities of daily living but had some degree of slowness and difficulty, and did not show signs of depression. Three months following the treatment intervention, repeated administration of screening measures suggested that no further deterioration in cognition, motor symptoms, or independence with activities of daily living had taken place, but that Participant 1 had developed moderate clinical depression. Screening measures also suggested that Caregiver 1 had mild cognitive impairment, with a MoCA score that bordered the cut off score that would suggest possible dementia. Since the MoCA was only administered once on the caregivers, it is not known if Caregiver 1's cognitive impairment progressed during the study period.

In regard to Participant 1's self-reported performance on and satisfaction with his self-identified treatment goals, despite unanimous agreement between Participant 1, Caregiver 1, and the principal investigator that Participant 1 had achieved all five of his treatment goals by the end of his participation in the CO-OP program, quantitative and qualitative measures suggested that Participant 1's performance on and satisfaction with self-identified treatment goals did not benefit from his participation in the CO-OP. The lack of change in average COPM performance and satisfaction scores from the pre-intervention phase to the post intervention phase is consistent with Participant 1's contradictory interview responses throughout the study period in which he described mixed feelings about the effects of the CO-OP: throughout the study period, Participant 1 had stated that he found the CO-OP global strategy helpful to structure his thinking when approaching problems, but post-intervention, he stated that he felt he actually had more difficulty with problem solving than he had prior to participating in the CO-OP. Three months following treatment, Participant 1 stated that he felt that his ability to learn new tasks had improved "a bit," but he also said that he was no longer using the CO-OP global strategy. The decrease in Participant 1's average COPM satisfaction scores and his cessation of using the CO-OP global strategy between the immediate post-intervention phase and the three month follow-up may be partly attributable to the moderate clinical depression that Participant 1 appeared to have developed by the three month follow-up. Caregiver 1's limited coaching may also have contributed to Participant 1's cessation of using the CO-OP global strategy once treatment had ended: compared to the other two caregivers that participated in the study, Caregiver 1 took on much less of a coaching role for Participant 1 during the CO-OP program. Caregiver 1's limited coaching may have been partly related to her own cognitive impairment and also may have been related to her stated belief that Participant 1 didn't need her coaching to complete his CO-OP

homework. As a self-report measure, the lack of significant change in COPM scores for Participant 1 may also have been partly attributable to tendencies that were observed in Participant 1 to have low confidence in his abilities in general and to minimize his accomplishments when discussing how his CO-OP treatment sessions had gone. Lastly, the lack of change in COPM scores may also have been partly attributable to Participant 1's stated hope that participating in the CO-OP would directly improve his Parkinson's disease, which was unfortunately unrealistic and was not the goal of the treatment program. Participant 1 felt that the CO-OP program had been helpful to structure his thinking, but differently from the other two participant/caregiver pairs, neither Participant 1 nor Caregiver 1 directly expressed feelings that the CO-OP had helped to improve their awareness of Participant 1's difficulties with his thinking. It is possible that for both Participant 1 and Caregiver 1, cognitive impairment may have limited their abilities to develop better awareness of Participant 1's difficulties with his thinking; of note, Participant 1 and Caregiver 1 had the two lowest MoCA scores (18/30 and 17/30 respectively) of the six individuals who took part in the study. In all their interviews, there was a striking difference between Participant 1 and Caregiver 1's opinions about Participant 1's cognitive impairment: Participant 1 seemed to feel that his thinking difficulties were very problematic for him while Caregiver 1 did not believe that Participant 1 had much difficulty with his thinking abilities at all. Caregiver 1's responses during her interviews were consistent with quantitative findings from the COPM in that she felt that the CO-OP had not had much effect on Participant 1's ability to complete cognitive components of day to day tasks; however, Caregiver 1's feelings that the CO-OP didn't provide much benefit were expected since Caregiver 1 did not feel that Participant 1 had much difficulty with his thinking abilities in the first place.

Participant 1's self-reported health-related quality of life did not appear to have changed during the study period according to results from quantitative and qualitative measures. Findings from statistical and visual analysis of PDQ-39 Summary Index scores suggested that no significant change had taken place. Results from the primary qualitative measure (in-depth interviews) were inconclusive: Participant 1 had stated at his mid- and post-intervention interviews that there had been a small improvement in his quality of life since he had begun participating in the CO-OP but he was unable to specify how his life had changed. Throughout the study period, Participant 1 had difficulty separating his thoughts and feelings about his motor symptoms and his thoughts and feelings about his cognitive symptoms of Parkinson's disease. It is possible that the lack of change on Participant 1's self-reported health-related quality of life measures were related to the difficulty that Participant 1 had in thinking about his motor symptoms and cognitive symptoms separately.

For Caregiver 1, quantitative and qualitative results suggested that the CO-OP program had no effect on her burden as a caregiver or on her quality of life; however, potential change in these areas was limited by a floor effect: throughout the study period, Caregiver 1 had consistently indicated on the ZBI measures that she did not feel highly burdened as a caregiver and she stated during all of her in depth interviews that Participant 1's difficulties with his thinking did not have an effect on her quality of life. It is impossible to know if the CO-OP may have had an effect on Caregiver 1's caregiver burden or her quality of life if she had in fact felt that Participant 1's difficulties with his thinking were having a negative effect on her life at any point during the study period.

5.1.2 Case 2: Participant 2 and Caregiver 2

Screening measures suggested that prior to beginning treatment, Participant 2 had mild cognitive impairment, was experiencing motor symptoms of Parkinson's disease on one side of his body, was completely independent with activities of daily living but had some degree of slowness and difficulty, and did not show signs of depression. Three months following the treatment intervention, repeated administration of screening measures suggested that no further deterioration in cognition, motor symptoms, or independence with activities of daily living had taken place, and Participant 2 continued to show no signs of clinical depression. Screening measures also suggested that Caregiver 2 had normal cognition.

In regard to Participant 2's self-reported performance on and satisfaction with his self-identified treatment goals, quantitative and qualitative measures suggested that Participant 2 had benefited in some ways from his participation in the CO-OP and that improvements were maintained three months following treatment. Statistical and visual analysis suggested that average COPM performance scores had improved, but that average COPM satisfaction scores had not changed. On the COPM scale, there had been a clinically significant improvement in average COPM performance scores and in average COPM satisfaction scores across the study period. Participant 2's interview responses provided details that helped to explain the slightly inconsistent quantitative results: although Participant 2 felt that his memory difficulties had not improved, he felt that the CO-OP program had helped him to achieve his treatment goals by structuring the way that he thinks and by making him more aware of what his thinking difficulties are. He also felt that the CO-OP program had improved his ability to learn new tasks, but that it had not improved his ability to solve problems. Maintenance of improved COPM

scores at the three month follow-up was likely related to the fact that Participant 2 was continuing to use the CO-OP global strategy on his own three months following treatment. Of note, Participant 2 was the only participant who was still using the CO-OP global strategy by the three month follow-up. Participant 2 may have been particularly more motivated than other participants to continue using the CO-OP global strategy on his own because, as he said during the treatment program, the CO-OP global strategy was similar to a strategy he had used and found helpful in his work as a CEO. Participant 2's continued use of the CO-OP global strategy three months following treatment may also have been related to the fact that Participant 2 was the only participant who had not develop new health problems following the end of treatment. Participant 2's benefit from participating in the CO-OP program and his continued use of the global strategy three months following treatment may also have been partly attributable to Caregiver 2's coaching style: Caregiver 2 was naturally soft spoken, but very supportive; during CO-OP treatment sessions, Caregiver 2 very quickly (within the first session) learned to provide the correct balance of support while also allowing Participant 2 to discover his own successful plans with which to achieve his treatment goals using the 'Goal-Plan-Do-Check' global strategy. Although Caregiver 2 felt that the CO-OP had helped to provide a structure for Participant 2's thinking, her thoughts about the effect of the CO-OP on Participant 2's thinking abilities were inconsistent with COPM scores in that Caregiver 2 did not feel that Participant 2's thinking difficulties had improved during treatment. Caregiver 2 did feel, however, that the CO-OP program had improved both Participant 2's awareness and her own awareness of his cognitive difficulties.

In regard to Participant 2's self-reported health-related quality of life, quantitative and qualitative results suggested that his health-related quality of life had improved during the study period. Statistical and visual analysis of PDQ-39 Summary Index scores showed an improvement (decrease in scores) from the pre-intervention phase to the post-intervention phase. Results from qualitative interviews with Participant 2 were consistent with quantitative results, in that he stated at mid- and post-intervention that his quality of life had improved since he began participating in the CO-OP; however, he also stated at mid-intervention and the three month follow-up that he didn't feel that his difficulties with his thinking had much effect his quality of life. Participant 2's positive comments during his interviews regarding his quality of life were consistent with his overall presentation as an optimist throughout the study period. Because of his optimistic personality, Participant 2 may have been more likely than other participants to have responded that he felt that he had benefited from the treatment program.

For Caregiver 2, quantitative and qualitative results suggested that, although caregiver stress was low during the entire study period, caregiver stress may have further decreased slightly over the study period. Statistical and visual analysis of ZBI scores suggested that caregiver stress decreased slightly following the pre-intervention phase, but also suggested that caregiver stress was not high at any point during the study period. Results from qualitative interviews are consistent with quantitative results: although Caregiver 2 stated throughout the study period that she did not think that Participant 2's thinking difficulties affected her quality of life and that the CO-OP had had no effect on her quality of life, her feelings that the CO-OP had helped her to cope better and adapt to Participant 1's difficulties with his thinking may be reflected in the small improvement that was seen in ZBI scores following the intervention phase.

Compared to the other two caregivers, Caregiver 2 made more detailed, insightful comments about her observations of Participant 2's cognition, the effects of his cognitive difficulties on both their lives, and the effects of the CO-OP. It is possible that the difference in number and quality of insightful comments from Caregiver 2 may have been partly attributable to the fact that Caregiver 2 was the only caregiver who tested within normal cognitive range on the MoCA.

5.1.3 Case 3: Participant 3 and Caregiver 3

Screening measures suggested that prior to beginning treatment, Participant 3 had mild cognitive impairment, was experiencing motor symptoms of Parkinson's disease on one side of his body, was completely independent with activities of daily living but had some degree of slowness and difficulty, and did not show signs of depression. Three months following the treatment intervention, repeated administration of screening measures suggested that no further deterioration in Participant 3's cognition or independence with activities of daily living had taken place, but that his motor symptoms had progressed to affect both sides of his body, although his balance was still unaffected. Participant 3 continued to show no signs of clinical depression at the three month follow-up. Screening measures also suggested that Caregiver 3 had mild cognitive impairment.

In regard to Participant 3's self-reported performance on and satisfaction with his self-identified treatment goals, quantitative and qualitative measures suggested that Participant 3 had benefited in some ways from participating in the CO-OP treatment program. COPM scores suggested that Participant 3's performance on and satisfaction with self-identified treatment goals had improved but that improvements were not maintained following the end of treatment. Participant 3's responses at his interviews confirmed that he found the CO-OP treatment program

beneficial to structure his thinking in order to reach his goals, particularly for difficulties he experienced with his memory, although he had stated from the start of the study period that he did not feel that he had difficulty with problem solving or learning new tasks and later stated that he felt that the CO-OP had no effect on these abilities for him. The lack of maintenance of improvements in COPM scores three months following treatment may have been related to the fact that Participant 3 was no longer using the CO-OP global strategy. Participant 3's cessation of use of the CO-OP global strategy by the three month follow-up may have been partly attributable to stress he and his wife were under due to news they had recently received that Participant 3 had possible bladder cancer and further tests were planned. Another contributing factor to Participant 3's cessation of use of the CO-OP global strategy may have been his tendency to prefer to rely on his wife to assist him to use the global strategy rather than attempt to use the global strategy independently. It is not known if the progression of Participant 3's motor symptoms contributed in any way to Participant 3's cessation of using the CO-OP global strategy: Participant 3 made no comments during his interviews in regard to progression of motor symptoms and his motor symptoms were not noticeably worse when observed by the principal investigator at Participant 3's three month follow-up, but there is a possibility that his progressed motor symptoms could have contributed to his cessation of use of the global strategy. Caregiver 3 also felt that Participant 3's difficulty with his memory had improved during and immediately following treatment, but she felt that his memory had actually worsened by the three month follow-up. Caregiver 3 herself attributed Participant 3's worsening memory to the stress he was under from negative news he had recently received about his health. Throughout the study period, Caregiver 3 did not feel that Participant 3 had much difficulty with problem solving or with learning new

tasks, therefore Caregiver 3's feelings that the CO-OP program had no effect on Participant 3's problem solving or learning skills was not unexpected.

In regard to Participant 3's self-reported health-related quality of life, results from quantitative and qualitative measures were inconsistent with each other. Statistical and visual analysis of PDQ-39 Summary Index scores suggested that scores varied. Participant 3's interview responses were inconsistent with quantitative results in that he stated that he felt that participating in the CO-OP treatment program had improved his quality of life, specifically by improving his awareness of his difficulties with his thinking and teaching him how to structure his thinking differently in order to achieve his treatment goals.

In regard to Caregiver 3's self-reported caregiver stress and quality of life, quantitative and qualitative results explained each other. Statistical and visual analysis of ZBI scores suggested that there was a decrease in caregiver stress from the pre-intervention phase to the post intervention phase, but that caregiver stress increased by the three month follow-up. Results from interviews with Caregiver 3 largely explained the findings from the ZBI scores: Caregiver 3 had stated at mid-intervention that she felt that Participant 3's difficulties with his thinking negatively affected her quality of life, but otherwise Caregiver 3 did not feel that Participant 3's difficulties with his thinking affected her quality of life at any other point during the study period. The increased ZBI score at the three month follow-up may be attributable to Caregiver 3's recent increase in stress she described that she felt related to the negative news she and Participant 3 had recently received about his health, and may have been unrelated to their participation in the CO-OP program. Despite the increased stress Caregiver 3 was feeling related to Participant 3's

health by the three month follow-up, ZBI scores were not high enough to indicate high caregiver stress at any point during the study period.

5.2 Quantitative and Qualitative Findings

Although statistical analysis of quantitative data showed some statistically significant changes in scores on the COPM, the PDQ-39, and the ZBI, statistical significance is meaningless unless observed changes are also clinically significant, which would demonstrate observable, meaningful changes had occurred for the participants and caregivers from participating in the CO-OP treatment program.

The CO-OP treatment program has been shown to affect performance on and satisfaction with self-identified treatment goals for individuals with Parkinson's disease, although the degree to which the CO-OP affects goal performance and satisfaction with performance can vary from one individual to another based on many factors. As stated in section 3.3.1.6, a two point change on any subscale within the COPM is considered to be clinically significant (Law, Baptiste, Carswell, McColl, Polatajko, & Pollock, 2005). In regard to clinically relevant findings from COPM scores, comparison of average COPM performance and satisfaction scores across phases for Participant 1 suggests that no clinically significant change occurred (*Table 4.2*); however, in comparison of average COPM performance and satisfaction scores across phases for Participant 2 (*Table 4.3*) and Participant 3 (*Table 4.4*), clinically significant changes were found. Specifically, average COPM performance scores for Participant 2 gradually improved through each phase until reaching clinical significance by the three month follow-up measure; average COPM satisfaction scores for Participant 2 reached a clinically significant improvement by the intervention phase and then plateaued for the remaining phases; average COPM performance and

satisfaction scores for Participant 3 each improved gradually until they reached clinical significance by the post-intervention phase, then returned to a clinically insignificant change from the pre-intervention phase scores by the three month follow-up phase.

According to qualitative data analysis findings, individuals with Parkinson's disease who participate in the CO-OP program are able to achieve their treatment goals in part because the CO-OP program improves individuals' awareness of their thinking difficulties and teaches individuals to structure their thinking differently. This increased awareness of thinking difficulties and differently structured thinking can be maintained over time if the CO-OP global strategy is used on a regular basis after direct treatment has finished. Findings from this study showed that long term follow through with use of the CO-OP global strategy can be difficult and can be limited by changes in health status and by the amount of coaching and support offered by caregivers, but can be easier for individuals who may already be familiar with a similar strategy.

According to quantitative results, the CO-OP treatment program appears to have no effect on health related quality of life for individuals with Parkinson's disease. As stated in section 3.3.1.7, a six point change in PDQ-39 scores is considered to be clinically significant (Fitzpatrick, Norquist, & Jenkinson, 2004). In regard to clinical relevance of findings from PDQ-39 scores, comparison of average PDQ-39 Summary Index scores across phases, no clinically relevant change in scores was found for any of the three participants (*Tables 4.5, 4.6, and 4.7*). The lack of clinically significant changes seen on PDQ-39 scores may have been confounded by the fact that most questionnaire items on the PDQ-39 refer to physical symptoms, and the proportion of the PDQ-39 devoted to cognitive symptoms may be too small for any changes that may have taken place in regard to cognitive symptoms to have been detected during the study

period. Indeed, qualitative results suggest that the CO-OP program can affect health-related quality of life by helping individuals with Parkinson's disease to restructure their thinking so that they can achieve self-identified goals related to everyday activities.

Quantitative results suggest that the CO-OP has no effect on quality of life for caregivers of individuals with Parkinson's-related cognitive impairment; however, in regard to clinical relevance of findings from ZBI scores, ZBI total scores were never high enough to suggest a high degree of caregiver burden for any of the three caregivers during any of the study phases (*Tables 4.8, 4.9, and 4.10*) (Rehabilitation Institute of Chicago, 2013; Schreiner, Morimoto, Arai, & Zarit, 2006). Despite the lack of clinically significant changes found in caregiver ZBI scores, the CO-OP has been shown to improve caregiver awareness of cognitive difficulties in individuals with Parkinson's disease, and this increased awareness in caregivers can improve caregivers' coping skills and empathy toward their loved ones with cognitive impairment. Clinically relevant changes to quality of life for caregivers in this study may not have been possible due to a floor effect because caregiver burden was already low for these caregivers. It is possible that caregivers with a high degree of caregiver burden prior to participating in the CO-OP may find that their caregiver burden decreases when they participate in the CO-OP because the increased awareness of their loved ones' cognitive difficulties that caregivers develop from participating in the CO-OP can improve caregivers' coping skills.

5.3 Potential Influence from Other Variables on Study Findings

Repeat measures of descriptive characteristics at the three month follow-up found that Participant 1 showed symptoms of depression according to his BDI score; he had scored within normal range on the BDI during study screening. The development of depression for Participant 1 certainly had the potential to negatively influence his self-perception (American Psychiatric Association, 2013). A change toward a negative self-perception would logically be reflected on self-report measures of an individual's performance level in meaningful activities and his or her satisfaction with his or her performance, and therefore may account for the decline in Participant 1's COPM performance and satisfaction scores at the three month follow-up. All other findings from descriptive characteristic measures at the three month follow-up were consistent with findings from the study screening, suggesting that study results were largely unaffected by any progression of participants' Parkinson's symptoms.

At the three month follow-up, Caregiver 3 mentioned that Participant 3 was having a biopsy in the near future to determine if he had bladder cancer. She was tearful when discussing the possibility that her husband may have cancer. It is possible that Caregiver 3's concern about this change in Participant 3's health may have negatively influenced her ZBI score at the three month follow-up interview (Wozniak & Iszyki, 2014).

During study screening, two of the three caregivers scored below normal on the MoCA. While Caregiver 3 scored only two points below normal range, Caregiver 1 scored nine points below normal range, which was very close to the cut-off of 16/30 which would have indicated that she was too cognitively impaired to participate in the study (Hoops, et al., 2009). Caregiver 1's comparatively low MoCA score suggests that her cognitive skills are lower than the skills of

Caregiver 2 and Caregiver 3, and therefore she may have less astute observational skills and less insight into her spouse's cognitive difficulties than the other caregivers. Therefore, Caregiver 1's feelings that Participant 1's cognitive difficulties were minimal may not be accurate. In addition, Caregiver 1's cognitive impairment may account for the fact that she was the only caregiver who did not mention an increased awareness of the nature of her spouse's cognitive difficulties or an improved ability to cope with those difficulties. Lastly, Caregiver 1's feelings that Participant 1's cognitive difficulties were minimal in comparison to the other caregivers' feelings about their spouses may explain why Caregiver 1's ZBI scores were lower than the ZBI scores of the other caregivers, since Caregiver 1 may not have had reason to experience much caregiver burden if she had limited awareness that Participant 1 had any cognitive difficulties in the first place.

5.4 Study Objectives: what was learned

In respect to the study objectives, the following information was learned:

Objective 1:

As described in section 5.1.4, the CO-OP protocol was effective for all three participants with Parkinson's-related cognitive impairment to reach their treatment goals for trained tasks of either basic or instrumental activities of daily living with individuals.

Objective 2:

The strategies taught by the CO-OP protocol were generalizable by participants to the same trained tasks when the tasks were completed outside of treatment sessions. This was evident when participants described that they were continuing to use the strategies that they had developed during treatment to continue to achieve / maintain those same treatment goals, such as

composing e-mail messages with fewer mistakes or being more reliable to remember to take medications on time.

Objective 3:

The strategies taught by the CO-OP protocol were transferable by participants to other tasks that were not trained in treatment sessions. This was evident by the participants' detailed self-reports of how they each used the global strategy to achieve the two treatment goals that they each identified at their pre-intervention interviews but were asked to work on by themselves, as well as by the participants' abilities to develop and successfully work on additional goals using the global strategy outside of treatment sessions.

Objective 4:

Only Participant 2 continued to actively use the strategies he had learned from the CO-OP treatment program by 3 months following the intervention. Participant 1's lack of follow through with using the CO-OP strategies following treatment may have been related to possible depression as per his BDI score at his three month follow-up interview. Immediately following completion of the treatment program, Participant 3 did not appear to have any motivation to continue to use the global strategy on his own, so the finding that he was no longer using the CO-OP strategies by three months following the intervention was not surprising.

Objective 5:

a.) The CO-OP training protocol appears to have had mixed results in regard to its effect on participants' perceived performance on, and satisfaction with, self-care, productivity, and leisure

occupations as measured using the COPM. Quantitative results suggest that the CO-OP training protocol had no significant effect on Participant 1's performance on or satisfaction with meaningful occupations. The only significant change seen in COPM scores for Participant 1 was in a downward direction at the three month follow-up. Since, by the three month follow-up, Participant 1 was no longer using the CO-OP strategies and his BDI score suggested possible depression, it is unlikely that the CO-OP training protocol had much influence on Participant 1's COPM scores at the three month follow-up. Quantitative results suggest that the CO-OP training protocol had both statistically and clinically significant benefits for Participant 2 and Participant 3 on their performance on and satisfaction with meaningful occupations. Similar to Participant 1, the fact that Participant 3 was no longer using the CO-OP strategies by the three month follow-up may account for the decline in his COPM scores back to baseline by that point.

b.) While statistical analysis of PDQ-39 Summary Index scores suggests there may have been an improvement in all three participants' self-rated health-related quality of life from participating in the CO-OP training protocol, none of the changes that took place in the PDQ-39 Summary Index scores were clinically significant. Qualitative results agree somewhat with quantitative findings on participants' self-rated health-related quality of life. None of the participants stated that they had experienced any improvements in losses they had experienced such as losses of skills related to productivity, communication, independence, socialization, or identity/roles over the study period; however, all participants felt that the CO-OP program had improved their quality of life by increasing their awareness of their thinking difficulties and helping them to organize how they think in order to approach problems.

c.) While statistical analysis of ZBI scores gave inconsistent results regarding the effect of the CO-OP treatment on caregiver stress, all ZBI scores for all caregivers were below the cut-off that would indicate a high caregiver burden was present, suggesting that caregiver stress had not been very high for any of the caregivers either prior to participating in the CO-OP program or at any point during the study period. It is possible then, that the level of stress that caregivers were experiencing prior to participating in the CO-OP program was so relatively low that a floor effect made it unlikely for the CO-OP program to influence caregiver stress (Pascoe & Edvardsson, 2015).

d.) Qualitative results helped to inform the quantitative results from COPM measures by providing detailed descriptions of participants' perceptions of their own cognitive abilities. All three participants found the CO-OP treatment program helpful to increase their awareness of their difficulties with their thinking and to help to organize how they think and solve problems. By the three month follow-up, none of the participants felt that they had much difficulty solving problems, but they also generally felt that this lack of difficulty wasn't a change from their baseline abilities. Participant 1 and Participant 2 did not feel that their difficulties with their memory had changed during treatment, but Participant 3 felt that his memory difficulty had improved. The caregivers, on the other hand, while they agreed that the CO-OP program had helped to increase the participants' awareness of their thinking difficulties, they did not feel that the participants' difficulties with problem solving or other cognitive abilities had improved during the study period. The only exception to this was that Caregiver 3 felt that Participant 3's short-term memory had improved during treatment, but then had worsened again by the three month follow-up.

e.) The CO-OP protocol did not seem to have any effect on quality of life for the caregivers that participated in this study. During their interviews, all three caregivers generally felt that the participants' difficulties with their thinking had little to no effect on their quality of life, and that their quality of life did not change over the course of the CO-OP treatment program.

In addition to findings that informed the study's objectives, there were several other meaningful observations made during this study. Firstly, all three participants with Parkinson's showed a high level of motivation to attend each treatment session and perseverance to follow through with all of their homework, even when the work was sometimes difficult. In the principal investigator's clinical experience, individuals with Parkinson's are generally much less motivated than the three participants that took part in this study. In addition, amotivation is known to be a common symptom of Parkinson's disease (Leroi, et al., 2011). It is possible that the atypically high level of motivation that the participants with Parkinson's disease demonstrated throughout the study period was because the participants were self-selected for the study, and therefore would be inherently more motivated to participate in a treatment program than individuals with Parkinson's who did not express interest in the study.

Secondly, all three caregivers chose to continue to attend all CO-OP treatment sessions, even though they had all been given permission to stop attending the sessions once they felt they had a good understanding of the global strategy. As an explanation as to why they chose to continue attending treatment sessions, all three caregivers stated that they wished continue attending in order to continue to support their spouses. The fact that all three caregivers chose to continue to attend every treatment session, even though they were aware that they were not required to, suggests that the three caregivers were all very supportive of their spouses with

Parkinson's disease. It is possible that the high level of support offered by all three caregivers was also related to the self-selection process, in that caregivers who are very supportive of their spouses may have been more likely to express interest in participating in the study than caregivers who may be less supportive or less able to provide support.

Thirdly, this author (the treating therapist and principal investigator) found the CO-OP protocol to be quite different from typical occupational therapy treatment approaches in which individuals receiving therapy are usually overtly taught by the therapist how to perform an activity. Adhering to CO-OP protocol requirements to provide as little input as possible in order to allow the participants to learn how to develop successful plans to reach their goals on their own was very difficult for the therapist / principal investigator. The intentional action of therapist reflection following each treatment session on what had gone well, what had not gone well, and whether or not it was difficult to adhere to the CO-OP protocol was useful to improve and maintain the integrity of the treatment intervention. Reviewing the video recordings from the first three treatment sessions completed with each participant was also valuable to critically analyze the delivery of the CO-OP treatment program in order to improve and maintain its integrity. Because of the learning process inherent in offering a new treatment program for the first time, the quality of the CO-OP treatment program provided to each participant was not equal. Participant 2 and Participant 3 received a more clearly organized treatment program that adhered better to the CO-OP protocol than Participant 1 received.

Fourthly, it appeared to be generally more effective for participants to complete the "Do" and "Check" steps of the global strategy as homework rather than complete these steps in the presence of the therapist. The participants stated that they felt more comfortable executing their

plans when they could work on their own without being observed, and time usually didn't permit for all three of the "Plan," "Do," and "Check" steps to be completed within the same treatment session. Moving the "Do" and "Check" steps to homework requirements also had the effect that fewer home visits were required from the therapist.

5.5 Comparisons of Study Findings to Existing Literature

Findings from this study are consistent with findings from other studies on the effects of the CO-OP for adults with cognitive impairment that show that the CO-OP treatment protocol can be effective for individuals to reach their treatment goals for trained tasks, that the strategies that individuals are taught during CO-OP treatment sessions can be generalized to the same trained tasks outside of treatment sessions, and that CO-OP strategies learned in treatment sessions can be transferred by the individuals to untrained tasks (Dawson et al., 2009; Dawson et al., 2013; Skidmore et al., 2011; Ng et al., 2013; Poulin et al., 2016).

Although the results from this study are difficult to compare with findings from other studies on the effects of cognitive training on cognitive impairment in Parkinson's disease because of its unique intervention and single subject design, findings from this study are not consistent with findings from other studies on the effects of cognitive training on cognitive impairment in Parkinson's disease in that this study found no improvement in quantitative measures of participants' underlying cognitive skills such as short-term memory (as per MoCA scores at screening and at three months following the intervention); however, qualitative results and the principal investigator's observations suggested that improvements took place in task organization, problem-solving skills, and in participants' insight into their cognitive limitations. Despite the discrepancy in quantitative cognitive skill findings from other studies, no direct

changes were expected in underlying cognitive skills in this study because the CO-OP is a task-based cognitive strategy treatment approach and does not directly address underlying cognitive skills. This study was consistent with findings from Peña et al. (2014) in that improved occupational performance in meaningful activities was demonstrated for two of the three participants with Parkinson's, and that the reasons for improvement may be attributable to the strategic learning and transfer techniques emphasized within the CO-OP program, similar to the techniques emphasized in the program offered by Peña et al. (2014). Although all three prior studies on the effects of cognitive rehabilitation in Parkinson's disease found that results were maintained for several months following intervention (Petrelli et al., 2014 & 2015; Mohlman et al., 2010; Sinforiani et al., 2004), in this study, improved occupational performance in meaningful activities was maintained at three months following the CO-OP intervention for only Participant 2 as per COPM performance and satisfaction scores. The poor maintenance of treatment effects for Participant 1 and Participant 3 is correlated with the fact that neither Participant 1 nor Participant 3 were still using the CO-OP global strategy on their own by the three month follow-up, while Participant 2 had continue to use the global strategy on his own. This correlation suggests that continued use of the CO-OP global strategy following the end of treatment is necessary in order for benefits in occupational performance to be maintained. Findings from this study that the CO-OP intervention had no meaningful effects on health-related quality of life are consistent with findings from both Paris et al. (2011) and Petrelli et al. (2014). Since the PDQ-39 measures many more aspects that are known to affect health-related quality of life in Parkinson's disease than just cognition (Jenkinson, Fitzpatrick, & Peto, 2013), it is likely that the lack of clinically significant change in PDQ-39 results from this study reflects the fact that the CO-OP treatment program focused only on cognitive difficulties. During the qualitative

interviews, participants often found it challenging to separate their thoughts about their cognitive symptoms from their thoughts about the physical symptoms of their Parkinson's disease. The caregivers also found it challenging to separate the cognitive and physical symptoms of their spouses' Parkinson's disease when answering interview questions. The lack of focus of the CO-OP treatment program on physical difficulties related to Parkinson's may be reflected in the participants' and caregivers' responses to questions related to quality of life.

5.6 Limitations

Reliability of findings from this study is limited in part by the fact that the adherence to the CO-OP treatment protocol therapeutic approach could not be maintained as strictly at the start of the study period as it was later on once the treating therapist had gained experience and skill in administration of the treatment protocol. This variance in protocol adherence occurred because the CO-OP treatment protocol was new to the therapist providing it and because adjustments were made by the treating therapist to improve adherence to the CO-OP protocol as the therapist gained familiarity with the protocol over the progression of the study. Despite efforts that were made to provide treatment that adhered as well as possible to the CO-OP treatment protocol, the learning effect on the part of the treating therapist may have contributed to smaller treatment effects for Participant 1 than for Participants 2 and 3, since study enrollment was staggered for each participant / caregiver dyad.

The fact that this study design included only 4-5 data points in each data collection phase limited the appropriateness of the use of the celeration line to analyze changes in data trends across phases (Ottenbacher, 1986), and likely accounts for the inconsistencies seen between celeration line findings and standard deviation band findings. As discussed in the 'Results'

section, it is important to note that, when analyzing single subject data, consistency is known to be limited across different methods of quantitative analysis and therefore statistical analysis should be interpreted with great caution and should not replace visual analysis (Nourbaksh & Ottenbacher, 1994). In consideration of the conflicting findings between the standard deviation band / interquartile band method and the celeration line method, greater weight should be given to the findings from the standard deviation band / interquartile band method, since none of the data collected for this study includes the minimum of 7-9 data points per data collection phase recommended by Ottenbacher for appropriate use of the celeration line method (1986) and since analysis of such a small number of data points in each data phase was vulnerable to high variability in the baseline data collection phase. There were several instances in this study in which statistically impossible predictions were made by celeration line analysis trends: specifically, impossible predictions were made that ZBI scores for Caregiver 1 should decrease to impossible negative numbers following the pre-intervention phase and that COPM satisfaction scores for Participant 2 and COPM performance scores for Participant 3 should increase to impossibly high numbers past the end of the COPM scale. These statistically impossible predictions made by celeration line data analysis were directly related to the wide variation in data points collected in the pre-intervention phases, and would have been less likely to occur if the pre-intervention phases were long enough to include at least 7-9 data points, since longer pre-intervention phases would have reduced their vulnerability to data variation.

Although most standard deviation band / interquartile band statistical analysis measures did not find any meaningful effect of treatment, there was consistently less variation in data over progressive phases for nearly all measures. It is possible that this reduction in variation of data

may have been due to a practice effect as participants became more familiar with the measures over time. The wide variation in data during pre-intervention phases caused the standard deviation bands / interquartile bands from the pre-intervention phases to be quite wide in comparison narrower bands in later phases. If data collection phases had included more data points to improve the stability of the data in each phase as discussed in the previous paragraph, standard deviation bands may also have been narrower, particularly in the pre-intervention phases, and may have found more meaningful effects of treatment than what was found in this study.

The small number of study participants and the fact that all three participants with Parkinson's disease were Caucasian males and all three caregivers were Caucasian females prevent the results of this study from being generalizable to all individuals with Parkinson's-related cognitive impairment. As with any ethical study performed using human participants, the self-selection bias of the participants involved in this study also limits the generalizability of study results.

5.7 Clinical, Research, and Theoretical Implications

5.7.1 Clinical Implications

Findings from this study suggest that the resources required to administer the CO-OP to individuals with Parkinson's-related cognitive impairment are not as high as first anticipated for the following reasons: 1) Although a maximum of twelve treatment sessions were planned for each participant if needed, no participant needed more than eight treatment sessions to achieve all five of their treatment goals; 2) for treatment goals that were dependent on realistic, home-

like environments, participants generally preferred to complete the “Do” and “Check” steps of the global strategy at home on their own and then report back to the therapist at the next treatment session rather than be directly observed by the therapist. Allowing participants to complete these two global strategy steps on their own at home served to decrease their self-reported anxiety about being observed in their homes while they carried out their plans, and also allowed for more time in each treatment session to develop and refine plans and then discuss the success or lack of success of those plans at following treatment sessions.

The CO-OP treatment protocol was well received by all three participants and all three caregivers, suggesting that the protocol has acceptable face validity; however, feedback from study participants suggests that the CO-OP protocol instruction for participants to write out all of their CO-OP goal sheets by hand may be an inappropriate hardship for the Parkinson’s population, as handwriting is well known to be very challenging for individuals with Parkinson’s disease (Letanneux, Danna, Velay, Viallet, & Pinto, 2014). In future use of the CO-OP with individuals with Parkinson’s disease, participants could be instructed to use alternative recording methods such as typing, audio-recording, or dictating the information they wish to write in their goal sheets to the treating therapist or a caregiver.

Qualitative findings from this study suggest that the CO-OP treatment protocol is particularly beneficial to increase awareness of cognitive limitations for both individuals with Parkinson’s disease and for their caregivers. Increased awareness of their own cognitive limitations could be clinically beneficial for individuals with Parkinson’s disease, since reduced insight into one’s own cognitive limitations is known to be a symptom of cognitive impairment in Parkinson’s disease (Lehrner, et al., 2015) and is related to poor judgment regarding safety and

other decisions (Rizzo, Uc, Dawson, Anderson, & Rodnitzky, 2010). Increased awareness on the part of caregivers of their love ones' cognitive limitations has the possibility of improving empathy, tolerance, and coping skills of the caregivers, which can in turn help to reduce caregiver stress (Stokes, Combes, & Stokes, 2014).

Study findings suggest that consistent adherence to the CO-OP protocol by the treating therapist is critical to achieve successful clinical outcomes when using the CO-OP treatment program. In order to best ensure consistent quality of treatment, all individuals providing the CO-OP program should be experienced occupational or physiotherapists that have received 16 hours of training provided by a certified CO-OP instructor, as recommended by the original authors of the CO-OP (Polatajko & Mandich, 2004), should have read Polatajko & Mandich's 2004 publication: "Occupation in Children: The Cognitive Orientation to daily Occupational Performance (CO-OP) Approach, and should also achieve therapist certification by demonstrating competency in the CO-OP protocol to a certified CO-OP instructor. Where therapist certification in the CO-OP protocol is difficult to obtain for logistical reasons (as it was for the therapist / principal investigator of this study), video recording and review of treatment sessions, therapist reflection of how individual treatment sessions went and how well the CO-OP protocol is adhered to, and detailed discussion of individual treatment sessions with an expert (preferably a certified CO-OP instructor) can be beneficial to maintain the integrity and quality of the CO-OP treatment program being provided.

5.7.2 Research Implications

Although findings from this study on the effects of the CO-OP for individuals with Parkinson's-related cognitive impairment are promising, the use of a larger number of data points

in each data collection phase would have strengthened the reliability of quantitative results by improving the reliability of celeration line statistical analysis and by permitting the C statistic to be included as another appropriate data analysis method.

Since study findings suggest that long-term benefits of the CO-OP treatment protocol are dependent on participants' abilities to regularly practice what they have learned in treatment after treatment has finished, further research into how individuals with Parkinson's-related cognitive impairment can be successfully supported to maintain treatment gains after formal treatment has ended would be beneficial. This author speculates that caregivers may be able to play valuable roles in the maintenance of treatment results, since the CO-OP treatment protocol strongly suggests that a caregiver should attend treatment sessions to learn the CO-OP global strategy and act as a coach outside of treatment sessions for the individual receiving the CO-OP treatment program.

A large, randomized control trial with a more heterogeneous group of participants and caregivers would be needed to better define effects of the CO-OP program that could then be generalized to the larger population of individuals with Parkinson's-related cognitive impairment and their caregivers.

5.7.3 Theoretical Implications

The CO-OP treatment protocol fits well into the client-centered practice approach that has been integral to the guidelines of occupational therapy practice in Canada for more than thirty years (Law, Polatajko, Baptiste, & Townsend, 1997), in that goals that are set for treatment in the CO-OP treatment program are goals that have been chosen and defined as meaningful by

the client, and in the CO-OP program's prescribed use of the COPM as a tool with which to set treatment goals (Law, Baptiste, Carswell, McColl, Polatajko, & Pollock, 2005). Although client-centered practice is typically thought of as a collaborative approach between the client and the therapist in order to meet treatment goals (Law, Polatajko, Baptiste, & Townsend, 1997), the CO-OP approach is distinctive in its focus on giving a very large share of responsibility for the learning that takes place during treatment on the client himself or herself through its unique process of guided discovery (Polatajko & Mandich, 2004) which is necessary to foster generalizability and transferability of the strategies learned during treatment so that clients can be capable of utilizing the CO-OP strategies independently on any number or type of goals that are meaningful to them. It is this unique approach of providing considerable autonomy to clients during the treatment process that seems to make adherence to the CO-OP protocol a challenge for even experienced therapists, which necessitates self-monitoring on the part of the therapist and consultation with therapists who are experts in provision of the CO-OP in order to ensure that the integrity of the CO-OP treatment protocol is maintained.

5.8 Conclusions

Individuals with PD-related cognitive impairment are capable of successfully engaging in self-selected treatment goals that are trained during CO-OP treatment sessions, generalizing the CO-OP strategies they have learned in treatment in order to successfully engage in the same goals outside of treatment, and transferring their new knowledge of the CO-OP strategies in order to successfully engage in untrained goals independently. Treatment effects can be difficult to maintain beyond the end of formal treatment sessions due to issues such as deterioration in health of individuals with PD and limited coaching provided by caregivers to encourage

individuals with PD to continue using the CO-OP global strategy. The CO-OP protocol is helpful to increase awareness of cognitive difficulties for individuals with PD-related cognitive impairment and to increase caregiver awareness of these cognitive difficulties. Increased awareness of cognitive difficulties is helpful for individuals with PD-related cognitive impairment to learn to restructure their thinking in order to achieve goals related to day-to-day activities. Increased caregiver awareness of cognitive difficulties in their loved ones can help to improve caregivers' coping skills.

Findings suggest that further study is needed to better determine the CO-OP treatment protocol's potential to be beneficial for individuals with PD-related cognitive impairment and for their caregivers. Further single subject study should involve longer pre-intervention phases in order to reduce variability in baseline data and improve reliability and sensitivity of quantitative data analysis methods.

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APPENDICES

Have you been diagnosed with Parkinson's Disease?

Do you experience any difficulty completing
ROUTINE DAILY TASKS

because of changes with your thinking or memory
that are **NEW** since your diagnosis?

You may be eligible to participate in a **research study** using
an innovative therapy program aimed to help improve your
ability to complete routine daily tasks independently.

**Principal Investigator: Catherine Bryden Dueck, OTReg(MB)
Occupational Therapist**

**If you meet the following criteria and are interested in participating, please
contact Kelly Williams, Clinical Resource Nurse:**

(Ph: [REDACTED] E-mail: [REDACTED])

- Live with a spouse or other caregiver
- Live within the Winnipeg city limits
- Are willing to participate in up to 12 one-hour therapy sessions

APPENDIX B **Consent Form****RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM
FOR CAREGIVERS OF PARTICIPANTS WITH PARKINSON'S DISEASE****Title of Study:**

Determining the Applicability of the Cognitive Orientation to daily Occupational Performance (CO-OP) as a Meta-Cognitive Rehabilitation Strategy for Individuals with Cognitive Impairment in Parkinson's Disease

Principal Investigator:

Catherine Bryden Dueck, OTReg.(MB)
Master of Science in Rehabilitation student, University of Manitoba
Occupational Therapist, Movement Disorder Clinic, Deer Lodge Centre
Room 2W41, 2109 Portage Avenue, Winnipeg, Ph: [REDACTED]

Co-Investigators:

Dr. Jacquie Ripat, Associate Professor, University of Manitoba. Ph: [REDACTED]
Dr. Ruth Barclay-Goddard, Assistant Professor, University of Manitoba. Ph: [REDACTED]

You are being asked to participate in a Clinical Trial (a human research study). Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this clinical trial and you may discuss it with your neurologist, friends and family before you make your decision. This consent form may contain words that you do not understand. Please ask the principal investigator or study staff to explain any words or information that you do not clearly understand.

Purpose of Study

This research is being conducted to study the effects of a cognitive rehabilitation therapy program, the Cognitive Orientation to daily Occupational Performance (CO-OP), on individuals with Parkinson's disease-related cognitive impairment. You are being asked to take part in this study because: you have a diagnosis of Parkinson's Disease; you have identified that you have a live-in spouse or caregiver who is willing to participate in the study as well; you have mild cognitive impairment; you can do most routine daily activities independently; and you do not have depression. A total of three (3) participants and their primary significant others / caregivers will participate in this study.

This research is being done because currently, there is no known rehabilitative treatment program for cognitive impairment for individuals with Parkinson's disease that has any known effects on performance of routine daily activities or quality of life for individuals with Parkinson's or their significant others / caregivers.

Study Procedures

If you take part in this study, you will participate in the following tests and procedures:

To confirm study eligibility:

You will attend one (1) screening session with Kelly Williams, the Clinical Resource Nurse at the Movement Disorder Clinic, where you will complete four brief pencil-and-paper screening assessments that assess your cognition (Montreal Cognitive Assessment – MoCA), your independence level and speed with activities of daily living (Schwab & England Activities of Daily Living Scale – Schwab & England ADL Scale), the staging of your Parkinson’s disease signs (Hoehn & Yahr Scale), and your mood (Beck Depression Inventory – BDI). This screening session will take approximately 30 minutes.

Once your eligibility for the study has been confirmed and if you agree to continue with participation in the study, you will participate in the following four (4) study phases:

1. Initial Assessment Phase:

To establish baseline data prior to beginning the treatment intervention:

- A. On a Monday at least two (2) weeks prior to the start of treatment, you will attend one (1) data collection session with a research assistant at the Movement Disorder Clinic where you will complete the following:
- i.) Pre-intervention cognitive testing using the Stroop test. This test will take approximately 5 minutes.
 - ii.) Parkinson Disease Questionnaire-39 (PDQ-39) on a Monday at least two weeks prior to the start of treatment. The PDQ-39 is a self-administered questionnaire that measures health-related quality of life for individuals diagnosed with Parkinson’s disease. This questionnaire will take approximately 10-20 minutes.

Completion of the entirety of data collection period 1A will take approximately 15-20 minutes.

- B. On a Monday at least two (2) weeks prior to the start of treatment, on the same day as data collection session 1A, you will attend one (1) individual interview session with the principal investigator at the Movement Disorder Clinic, which will consist of the following:
- i.) A semi-structured interview using the Canadian Occupational Performance Measure (COPM). The COPM interview will focus on participant-centred problem identification, in which you will be asked to identify functional performance problems related to your Parkinson’s disease and cognitive functioning, rate those problems according to their importance, then rate those problems again according to your self-determined performance level and satisfaction. This portion of the interview session will take approximately 30-40 minutes.

- ii.) Seven (7) additional structured, open-ended interview questions. This portion of the interview session will take approximately 10-20 minutes.

This interview session will be audio recorded and written notes will also be taken by the principal investigator. Completion of the entirety of data collection period 1B will take approximately 40-50 minutes.

- C. You will be given four (4) additional copies of the PDQ-39 and the COPM to complete at home on your own over the next two (2) weeks after your first assessment according to the following schedule: Wednesday, Friday, Tuesday, Thursday. You will receive a phone call reminder from a research assistant on each day that you are expected to complete the PDQ-39 and the COPM. Each session that you complete at home on your own will take approximately 15-20 minutes.

Completion of the entirety of data collection period 1C will take approximately 60-80 minutes, divided equally over four (4) data collection days.

Intervention Phase:

- A. You will participate in a treatment protocol known as the Cognitive Orientation to daily Occupational Performance (CO-OP). The following describes the CO-OP treatment protocol that will be followed during the intervention phase of the study:

You will be participating in up to twelve (12) treatment sessions lasting 45-60 minutes at a frequency of two (2) sessions per week, for up to six (6) weeks, run by the principal investigator (an occupational therapist with nearly 7 years' experience working with individuals with Parkinson's disease at the Movement Disorder Clinic at Deer Lodge Centre, and who is also a graduate student). During these treatment sessions, you will be taught a problem-solving strategy that teaches individuals to monitor and regulate their own behavior. You will be guided by the principal investigator to select five (5) individual treatment goals to work toward achieving during treatment. Sessions will continue until all five (5) treatment goals have been met or until twelve (12) sessions have been completed, whichever occurs earlier. Initially, your caregiver will be required to attend your treatment sessions, so that your caregiver may be familiar with the treatment strategy in order to coach you when you utilize the strategy outside of treatment sessions without the principal investigator present.

At the beginning, treatment sessions will be completed in the Movement Disorder Clinic Occupational Therapy treatment room at Deer Lodge Centre. Later, treatment sessions may take place at a location of your own choosing, in which the participant-selected treatment goal(s) would normally occur. These locations may include your own home or other locations in the community, such as a grocery store, a park, a library, or your workplace.

Completion of the entirety of all treatment sessions will take a maximum of 9-12 hours, roughly divided equally over a maximum of twelve (12) treatment sessions.

- B. You will be given five (5) copies each of the PDQ-39 and the COPM to complete at home on your own following treatment session two (2), four (4), six (6), eight (8), and ten (10), for a total of five (5) assessments of each measure. Each day you complete both measures will take approximately 15-20 minutes.
Completion of the entirety of data collection period 2B will take approximately 75-100 minutes, divided equally over five (5) data collection days.
- C. You will attend one (1) interview session with the principal investigator at the Movement Disorder Clinic between treatment session six (6) and seven (7). This interview session will consist of seven (7) structured, open-ended interview questions. This interview session will be audio recorded and written notes will also be taken by the principal investigator. This session will take approximately 10-20 minutes.

2. Re-Assessment Phase:

To determine the effects of the treatment intervention:

- A. You will be given five (5) copies of the PDQ-39 and the COPM by a research assistant to complete at home on your own over two (2) weeks following your last treatment session. You will be asked to complete the measures according to the following schedule: Monday, Wednesday, Friday, Tuesday, and Thursday. You will receive a phone call reminder from a research assistant on each day that you are expected to complete the PDQ-39 and the COPM. Each session that you complete at home on your own will take approximately 15-20 minutes.
- B. You will attend one (1) interview session with the principal investigator at the Movement Disorder Clinic. This interview session will consist of seven (7) structured, open-ended interview questions. This interview session will be audio recorded and written notes will also be taken by the principal investigator. This session will take approximately 10-20 minutes.

Three-Month Follow-Up Phase:

To determine the long-term effects of the treatment intervention:

- A. You will attend one (1) data collection session at the Movement Disorder Clinic three (3) months following the end of treatment. You will repeat the following assessments with a research assistant:
- The PDQ-39
 - The COPM
 - The Montreal Cognitive Assessment, the Schwab & England ADL Scale, the Hoehn & Yahr Scale, and the Stroop task
- This data collection session will take approximately 45-50 minutes.

- B. You will attend one (1) interview session at the Movement Disorder Clinic with the principal investigator three (3) months following the end of treatment. This interview session will consist of seven (7) structured, open-ended interview questions. This interview session will be audio recorded and written notes will also be taken by the principal investigator. This session will take approximately 10-20 minutes.

The researcher may decide to take you off this study if you develop problems in your health that make it physically or cognitively too difficult or dangerous to participate in this study.

You can stop participating at any time. However, if you decide to stop participating in the study, we encourage you to talk to the study staff first.

If you are interested in learning the results of this study, the principal investigator will provide you with information on where you can view the completed thesis or any published article that may come as a result of this study.

Risks and Discomforts

Your condition may not improve or may worsen, as per the normal course of Parkinson's disease, while participating in this study. Sometimes it may be uncomfortable to talk about your feelings when you are asked about any problems you may have with your memory and learning new tasks, how these problems may affect your quality of life, and how these problems make you feel about yourself and your abilities.

Benefits

By participating in this study, you will be providing information to the study investigators that will show the effects of the CO-OP for the treatment of Parkinson's disease-related cognitive impairment. There may or may not be direct functional benefit to you from participating in this study. We hope the information learned from this study will benefit other participants with Parkinson's disease-related cognitive impairment in the future.

Costs

All the procedures provided to you as part of this study will be free of cost.

Compensation for Participation

For participating in this study, any costs related to parking will be reimbursed.

Confidentiality

Information gathered in this research study may be published or presented in public forums, however your name and other identifying information will not be used or revealed. Medical records that contain your identity will be treated as confidential in accordance with the Personal Health Information Act of Manitoba. All study documents related to you will bear only your assigned participant code. Despite efforts to keep your personal information confidential, absolute

confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law.

The principal investigator, co-investigators, and a research assistant will be accessing your research records from this study for data analysis.

The University of Manitoba Health Research Ethics Board may review research-related records for quality assurance purposes.

All records will be kept in a locked secure area and only those persons identified will have access to these records. If any of your medical/research records need to be copied to any of the above, your name and all identifying information will be removed. No information revealing any personal information such as your name, address or telephone number will leave the Movement Disorder Clinic patient treatment areas at Deer Lodge Centre.

With your permission, your neurologist at the Movement Disorder Clinic will be notified of your participation in this study by letter.

Voluntary Participation/Withdrawal From the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your other medical care at the Movement Disorder Clinic. If your study investigator feels that it is in your best interest to withdraw you from the study, your study investigator will remove you without your consent.

We will tell you about any new information that may affect your health, welfare, or willingness to stay in this study.

Medical Care for Injury Related to the Study

You are not waiving any of your legal rights by signing this consent form nor releasing the investigator(s) or the sponsor(s) from their legal and professional responsibilities.

Questions

You are free to ask any questions that you may have about your treatment and your rights as a research participant. If any questions come up during or after the study, contact the principal investigator, Catherine Bryden Dueck, at [REDACTED].

For questions about your rights as a research participant, you may contact The University of Manitoba Health Research Ethics Board at [REDACTED].

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study with Catherine Bryden Dueck and/or the study staff. I have had my questions answered by them in

language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statement or implied statements. Any relationship (such as employee, student or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this clinical trial is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of my medical records by The University of Manitoba Health Research Ethics Board.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

I agree to being contacted in relation to this study. Yes No

I agree to my neurologist at the Movement Disorder Clinic being notified of my participation in this study. Yes No

Participant signature _____ Date _____
(day/month/year)

Participant printed name: _____

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent.

Printed Name: _____ Date _____
(day/month/year)

Signature: _____

Role in the study: _____ [This must be done by an authorized/qualified member of the research team i.e. principal investigator, clinical resource nurse, or research assistant]

Relationship to study team members: _____ [e.g. family member]

APPENDIX C Consent Form**RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM
FOR CAREGIVERS OF PARTICIPANTS WITH PARKINSON'S DISEASE****Title of Study:**

Determining the Applicability of the Cognitive Orientation to daily Occupational Performance (CO-OP) as a Meta-Cognitive Rehabilitation Strategy for Individuals with Cognitive Impairment in Parkinson's Disease

Principal Investigator:

Catherine Bryden Dueck, OTReg.(MB)
Master of Science in Rehabilitation student, University of Manitoba
Occupational Therapist, Movement Disorder Clinic, Deer Lodge Centre
Room 2W41, 2109 Portage Avenue, Winnipeg, Ph: [REDACTED]

Co-Investigators:

Dr. Jacquie Ripat, Associate Professor, University of Manitoba. Ph: [REDACTED]
Dr. Ruth Barclay-Goddard, Assistant Professor, University of Manitoba. Ph: [REDACTED]

You are being asked to participate in a Clinical Trial (a human research study). Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this clinical trial and you may discuss it with your neurologist, friends and family before you make your decision. This consent form may contain words that you do not understand. Please ask the principal investigator or study staff to explain any words or information that you do not clearly understand.

Purpose of Study

This research is being conducted to study the effects of a cognitive rehabilitation therapy program, the Cognitive Orientation to daily Occupational Performance (CO-OP), on individuals with Parkinson's disease-related cognitive impairment. You are being asked to take part in this study because: you are a live-in spouse or caregiver of an individual who has agreed to participate in the study; you are also willing to participate in the study; you do not have dementia. A total of three (3) participants and their primary significant others / caregivers will participate in this study.

This research is being done because currently, there is no known rehabilitative treatment program for cognitive impairment for individuals with Parkinson's disease that has any known effects on performance of routine daily activities or quality of life for individuals with Parkinson's or their significant others / caregivers.

Study Procedures

If you take part in this study, you will participate in the following tests and procedures:

To confirm study eligibility:

- You will attend one (1) screening session with Kelly Williams, the Clinical Resource Nurse at the Movement Disorder Clinic, where you will complete one brief pencil-and-paper screening assessment that assesses your cognition (Montreal Cognitive Assessment – MoCA). This screening session will take approximately 10 minutes.

Once your eligibility for the study has been confirmed and if you agree to continue with participation in the study, you will participate in the following four (4) study phases:

3. Initial Assessment Phase:

To establish baseline data prior to beginning the treatment intervention:

- A. On a Monday at least two weeks prior to the start of your spouse's / care recipient's treatment program, you will attend one (1) baseline data collection session with a research assistant at the Movement Disorder Clinic, where you will complete the Zarit Burden Interview (ZBI), which assesses your perception of your burden as a caregiver. This session will take approximately 5-10 minutes.
- B. On a Monday at least two weeks prior to the start of your spouse's / care recipient's treatment program, on the same day as data collection session 1A, you will attend one (1) interview session with the principal investigator at the Movement Disorder Clinic. This interview session will consist of seven (7) structured interview questions. This interview session will be audio recorded and written notes will also be taken by the principal investigator. This session will take approximately 10-20 minutes.
- C. You will be given four (4) additional copies of the Zarit Burden Interview (ZBI) to complete at home on their own over the next two (2) weeks after their first assessment according to the following schedule: Wednesday, Friday, Tuesday, and Thursday. You will receive a phone call reminder from a research assistant on each day that you are expected to complete the ZBI. Each session that you complete at home on your own will take approximately 5-10 minutes.

4. Intervention Phase:

- A. Your significant other / care recipient with Parkinson's disease will attend up to twelve (12) treatment sessions lasting 45-60 minutes at a frequency of two (2) sessions per week, for up to six (6) weeks, run by the principal investigator (an occupational therapist with nearly 7 years' experience working with individuals with Parkinson's disease at the Movement Disorder Clinic at Deer Lodge Centre, and who is also a graduate student).

During these treatment sessions, your significant other / care recipient will be taught a problem-solving strategy that teaches individuals to monitor and regulate their own behavior. Your significant other / care recipient will be guided by the principal investigator to select five (5) individual treatment goals to work toward achieving during treatment. Sessions will continue until all five (5) treatment goals have been met or until twelve (12) sessions have been completed, whichever occurs earlier.

At the beginning, treatment sessions will be completed in the Movement Disorder Clinic Occupational Therapy treatment room at Deer Lodge Centre. Later, treatment sessions may take place at locations of the participant's own choosing, in which the participant-selected treatment goal(s) would normally occur. Locations may include the participant's own home or other locations in the community, such as a grocery store, a park, a library, or the participant's workplace.

Initially, you will be required to attend your significant other's / care recipient's sessions, so that you may become familiar with the treatment strategy in order to provide coaching when your significant other / care recipient utilizes the strategy outside of treatment sessions without the principal investigator present.

Completion of the entirety of all treatment sessions will take a maximum of 9-12 hours, roughly divided equally over a maximum of twelve (12) treatment sessions.

- B. You will be given five (5) copies of the Zarit Burden Interview (ZBI) to complete at home on your own following treatment session two (2), four (4), six (6), eight (8), and ten (10), for a total of five (5) assessments of each measure. Each day you complete the measure will take approximately 5-10 minutes. You will receive telephone reminders by a research assistant to complete the ZBI according to the above schedule.
- C. You will attend one (1) interview session with the principal investigator at the Movement Disorder Clinic between treatment session six (6) and seven (7). This interview session will consist of seven (7) structured, open-ended interview questions. This interview session will be audio recorded and written notes will also be taken by the principal investigator. This session will take approximately 10-20 minutes.

5. Re-Assessment Phase:

To determine the effects of the treatment intervention:

- A. You will be given five (5) copies of the Zarit Burden Interview (ZBI) by a research assistant to complete at home on your own over two (2) weeks following your last treatment session. You will be asked to complete the measure according to the following schedule: Monday, Wednesday, Friday, Tuesday, and Thursday. You will receive a phone call reminder from a research assistant on each day that you are expected to complete the ZBI. Each session that you complete at home on your own will take approximately 5-10 minutes.

- B. You will attend one (1) interview session with the principal investigator at the Movement Disorder Clinic. This interview session will consist of seven (7) structured, open-ended interview questions. This interview session will be audio recorded and written notes will also be taken by the principal investigator. This session will take approximately 10-20 minutes.

6. Three-Month Follow-Up Phase:

To determine the long-term effects of the treatment intervention:

- A. You will attend one (1) data collection session at the Movement Disorder Clinic three (3) months following the end of treatment. You will be given one (1) copy of the Zarit Burden Interview by a research assistant to complete. This session will take approximately 5-10 minutes.
- B. You will attend one (1) interview session at the Movement Disorder Clinic with the principal investigator three (3) months following the end of treatment. This interview session will consist of seven (7) structured, open-ended interview questions. This interview session will be audio recorded and written notes will also be taken by the principal investigator. This session will take approximately 10-20 minutes.

The researcher may decide to take you off this study if you develop problems in your health that make it physically or cognitively too difficult or dangerous to participate in this study.

You can stop participating at any time. However, if you decide to stop participating in the study, we encourage you to talk to the study staff first.

If you are interested in learning the results of this study, the principal investigator will provide you with information on where you can view the completed thesis or any published article that may come as a result of this study.

Risks and Discomforts

Sometimes it may be uncomfortable to talk about your feelings as a caregiver when you are asked about any problems your care recipient / significant other may have with his or her memory and learning new tasks, and how these problems may affect your quality of life.

Benefits

By participating in this study, you will be providing information to the study investigators that will show the effects of the CO-OP for the treatment of Parkinson's disease-related cognitive impairment. There may or may not be a direct benefit to you from participating in this study. We hope the information learned from this study will benefit other participants with Parkinson's disease-related cognitive impairment and their caregivers / significant others in the future.

Costs

All the procedures provided to you as part of this study will be free of cost.

Payment for Participation

For participating in this study, any costs related to parking will be reimbursed.

Confidentiality

Information gathered in this research study may be published or presented in public forums, however your name and other identifying information will not be used or revealed. Medical records that contain your identity will be treated as confidential in accordance with the Personal Health Information Act of Manitoba. All study documents related to you will bear only your assigned participant code. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law.

The principal investigator, co-investigators, and a research assistant will be accessing your research study records from this study for data analysis.

The University of Manitoba Health Research Ethics Board may review research-related records for quality assurance purposes.

All records will be kept in a locked secure area and only those persons identified will have access to these records. If any of your medical/research records need to be copied to any of the above, your name and all identifying information will be removed. No information revealing any personal information such as your name, address or telephone number will leave the Movement Disorder Clinic patient treatment areas at Deer Lodge Centre.

Voluntary Participation/Withdrawal From the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your or your care recipient with Parkinson's disease's other medical care at the Movement Disorder Clinic. If your study investigator feels that it is in your best interest to withdraw you from the study, your study investigator will remove you without your consent.

We will tell you about any new information that may affect your health, welfare, or willingness to stay in this study.

Medical Care for Injury Related to the Study

You are not waiving any of your legal rights by signing this consent form nor releasing the investigator(s) or the sponsor(s) from their legal and professional responsibilities.

Questions

You are free to ask any questions that you may have about your treatment and your rights as a research participant. If any questions come up during or after the study, contact the principal investigator, Catherine Bryden Dueck, at [REDACTED].

For questions about your rights as a research participant, you may contact The University of Manitoba Health Research Ethics Board at [REDACTED].

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study with Catherine Bryden Dueck and/or the study staff. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statement or implied statements. Any relationship (such as employee, student or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this clinical trial is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of my medical records by The University of Manitoba Health Research Ethics Board.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

I agree to being contacted in relation to this study. Yes No

Participant signature _____ Date _____
(day/month/year)

Participant printed name: _____

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent.

Printed Name: _____ Date _____
(day/month/year)

Signature: _____

Role in the study: _____ [This must be done by an authorized/qualified member of the research team i.e. principal investigator, clinical resource nurse, or research assistant]

Relationship to study team members: _____ [e.g. family member.]

APPENDIX D Pre-Intervention Participant Interview Guide

Participant interview questions 2 and 3 are sourced from the WHODAS 2.0 (World Health Organization, 2011).

1. Do you feel that you have problems with your memory? Can you give some examples?
2. Can you describe any difficulty you have in learning new tasks (for example, how to get to a new place)?
3. How much difficulty do you have analyzing and finding solutions to problems in day-to-day life?
4. How do your difficulties with your thinking make you feel about yourself and your abilities?
5. How do your difficulties with your thinking affect your quality of life?
6. How do you think your difficulties with your thinking affect your significant other / caregiver?
7. What are you hoping to gain from participating in this treatment program?

APPENDIX E Pre-intervention Caregiver Interview Guide

Completed in the absence of the participant.

1. Do you feel that your significant other/care recipient has problems with his or her memory?
Can you give some examples?
2. Does your significant other/care recipient have difficulty learning new tasks (for example, how to get to a new place)? Can you describe these difficulties?
3. How much difficulty does your significant other/care recipient have analyzing and finding solutions to problems in day-to-day life? What is this like?
4. How do you think your significant other's/care recipient's difficulties with his/her thinking makes him/her feel about himself/herself and his/her abilities?
5. Does your significant other / care recipient utilize any strategies to manage his or her difficulties with his or her thinking?
6. How does your significant other's/care recipient's difficulties with his/her thinking affect your quality of life?
7. What are you hoping you and your significant other/care recipient will gain from participating in this treatment program?

APPENDIX F Mid-Intervention Participant Interview Guide

1. a) Do you feel that you have problems with your memory? Can you give some examples?
b) Have these changed since you began participating in the treatment program?
2. a) How much difficulty do you have learning new tasks (for example, how to get to a new place)?
b) Has this changed since you began participating in the treatment program?
3. a) How much difficulty do you have analyzing and finding solutions to problems in day-to-day life?
b) Has this changed since you began participating in the treatment program?
4. a) How do your difficulties with your thinking make you feel about yourself and your abilities?
b) Has this changed since you began participating in the treatment program?
5. a) How do your difficulties with your thinking affect your quality of life?
b) Has this changed since you began participating in the treatment program?
6. a) How do you think your difficulties with your thinking affect your significant other / caregiver?
b) Has this changed since you began participating in the treatment program?

APPENDIX G Mid-Intervention Caregiver Interview Guide

(Completed in the absence of the participant.)

1. a) Do you feel that your significant other/care recipient has problems with his or her memory? Can you give some examples?
b) Has this changed since he or she began participating in the treatment program
2. a) How much difficulty does your significant other/care recipient have learning new tasks (for example, how to get to a new place)?
b) Has this changed since he or she began participating in the treatment program?
3. a) How much difficulty does your significant other/care recipient have analyzing and finding solutions to problems in day-to-day life?
b) Has this changed since he or she began participating in the treatment program?
4. a) How do you think your significant other's/care recipient's difficulties with his/her thinking makes him/her feel about himself/herself and his/her abilities?
b) Has this changed since he or she began participating in the treatment program?
5. a) Does your significant other/care recipient utilize any strategies to manage his or her difficulties with his or her thinking?
b) Has this changed since he or she began participating in the treatment program?
6. a) How does your significant other's/care recipient's difficulties with his/her thinking affect your quality of life?
b) Has this changed since he or she began participating in the treatment program?

APPENDIX H Post-Intervention Participant Interview Guide

Used during post-intervention A phase and at three-month follow-up.

1. a) Do you feel that you have problems with your memory? Can you give some examples?
b) Have these changed since your participation in the treatment program?
2. a) How much difficulty do you have learning new tasks (for example, how to get to a new place)?
b) Has this changed since your participation in the treatment program?
3. a) How much difficulty do you have analyzing and finding solutions to problems in day-to-day life?
b) Has this changed since your participation in the treatment program?
4. a) How do your difficulties with your thinking make you feel about yourself and your abilities?
b) Has this changed since your participation in the treatment program?
5. a) How do your difficulties with your thinking affect your quality of life?
b) Has this changed since your participation in the treatment program?
6. a) How do you think your difficulties with your thinking affect your significant other / caregiver?
b) Has this changed since your participation in the treatment program?
7. a) Did you gain what you hoped for from participating in this treatment program?
b) What do you feel was missing from this treatment program that may have been helpful for you?
8. What did you like / not like about this program?

APPENDIX I Post-Intervention Caregiver Interview Guide

Completed in the absence of the participant during post-intervention A phase and at three-month follow-up.

1. a) Do you feel that your significant other/care recipient has problems with his or her memory? Can you give some examples?
b) Has this changed since he or she participated in the treatment program?
2. a) How much difficulty does your significant other/care recipient have learning new tasks (for example, how to get to a new place)?
b) Has this changed since he or she participated in the treatment program?
3. a) How much difficulty does your significant other/care recipient have analyzing and finding solutions to problems in day-to-day life?
b) Has this changed since he or she participated in the treatment program?
4. a) How do you think your significant other's/care recipient's difficulties with his/her thinking makes him/her feel about himself/herself and his/her abilities?
b) Has this changed since he or she participated in the treatment program?
5. a) Does your significant other/care recipient utilize any strategies to manage his or her difficulties with his or her thinking?
b) Has this changed since he or she participated in the treatment program?
6. a) How does your significant other's/care recipient's difficulties with his/her thinking affect your quality of life?
b) Has this changed since he or she participated in the treatment program?
7. a) Did you and your significant other/care recipient gain what you hoped for by participating in this treatment program?

- b) What do you feel was missing in this treatment program that may have been helpful for your significant other/care recipient or yourself?
8. What did you like / not like about this program?

APPENDIX J Participant Questionnaire: Possible Confounding Life Factors

1. Have any changes been made to your medication regime over the past two weeks? If so, when did this change (or these changes) take place? Did you experience any side effects related to this change (these changes)? If so, what were they and when did it (they) occur?
2. Have you experienced an illness, accident, or disruption in your eating or sleeping patterns over the previous two weeks? If so, can you please describe the event(s) and when it (they) occurred?
3. Have you experienced any other significant life events over the past two weeks (for example: a death, sudden critical illness, or accident in your family or circle of friends; a move from one home to another; a change in your employment status or the employment status of your caregiver / significant other; a falling out in a relationship with a close family member or friend; a large social event or a trip out of town)? If so, when did this occur?

APPENDIX K Caregiver Questionnaire: Possible Confounding Life Factors

1. Have you experienced an illness, accident, or disruption in your eating or sleeping patterns over the previous two weeks? If so, can you please describe the event(s) and when it (they) occurred?

2. Have you experienced any other significant life events over the past two weeks (for example: a death, sudden critical illness, or accident in your family or circle of friends; a move from one home to another; a change in your employment status or the employment status of your caregiver / significant other; a falling out in a relationship with a close family member or friend; a large social event or a trip out of town)? If so, when did this occur?