"Staying Strong = Staying Healthy" – How Parkinson Disease Progression Influences Care Dyads to Participate in Exercise

An Exploratory Descriptive Study

By

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Dedication

To my beloved son, **Conor,** I realize this endeavor did not come without a cost to you. Together, we survived a very difficult year…but we didn't let it knock us down. I hope you know that you are my most treasured gift; and I am honored and blessed to be your mom. Someday soon, you'll head off to college, and maybe you'll pursue an advanced degree, or maybe not. Either way, know that you can achieve anything with hard work, perseverance, a belief in yourself, and the support of some really good people. Thank you for believing in me and being proud of me. I feel the exact same way about you, and I will always love you "*to infinity and beyond*."

Just like moons and like suns,

With the certainty of tides,

Just like hopes springing high,

Still I'll rise.

—Maya Angelou, from the poem, "Still I Rise"

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I’ve dedicated this work to my son, **Conor**, and to my advisor, **Dr. Kristen Pickett**; and I hope they both know that my words on the previous page are genuine and come from a heart full of gratitude. I am also grateful for all of you…the mentors and the colleagues, who have become my friends, and for the friends and family who stood by me and supported me throughout this process. Thank you to each, and every one of you!

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Abstract

Introduction: Though the benefits of exercise for improving some symptoms of Parkinson disease (PD) are well known, research has largely overlooked two critically underserved groups: spousal caregivers and the care dyad, as a unit. For both members of the dyad, many barriers preclude their ability to participate in exercise. Dyadic interventions may overcome impediments to exercise and provide an opportunity for care dyads to respond to the health threat of PD with a shared focus and co-opted sense of ownership. This qualitative exploratory study examined factors influencing PD dyads' participation in exercise.

Methods: Semi-structured interviews were conducted with four dyads of individuals with probable PD (IPD) and their spousal caregivers (CG). Video and telephone conference interviews were conducted independently with each member of the dyad, and lasted 1½ to 3 hours. Interview questions were developed around the theory of interdependence and communal coping. All interviews were audio recorded and transcribed verbatim. Four researchers independently coded transcripts using open coding to identify underlying themes. Researchers grouped responses from interviews by codes to identify frequency, patterns of responses, and reoccurring themes using NVivo, version 12. Additionally, interviews were supplemented by the Canadian Occupational Performance Measure, as well as descriptive quantitative data derived from self-report measures (SRM) on PD symptoms, CG health conditions, quality of life (QOL), current levels of exercise, and stages of change as it relates to engaging in exercise.

Results: Four males, mean age 77.25 years with presumptive mid-stage PD, and four female CGs, mean age 72 years participated in the interviews. Three major themes were identified: 1) Progression of Parkinson Disease, 2) Perception of PD as a Threat, and 3) Factors Influencing Participation in Exercise. For individuals with PD, the "disease throws a curveball every day"; while for caregivers, PD means they are "trying to keep all the balls in the air." For the dyad, the threats imposed by the disease "keep them watching from behind" for each other's health and well-being. Taken together, the perceived threat of PD influences the dyads to either participate or consider participating in exercise, because "staying strong = staying healthy." Reflecting the qualitative results, the COPM indicated that IPDs identified their top problem areas related to PD symptoms; CGs focused on caregiving, all individuals indicated strength and stamina or exercise as at least one top problem area. Four IPDs and three CGs completed SRMs. IPDs reported better QOL than CGs (mean PDQ-39=23.23 pts vs. mean PDQ-C=36.32 pts). IPDs reported being in a higher stage of change for participation in physical activity and exercised more (1.5-5x/wk for 15-90 min/session) than CGs (0-5x/wk for 0-15 min/session).

Conclusion: Dyadic interventions may be especially relevant when each member of the dyad is motivated to respond to the health threat of PD for the benefit of one another and their relationship. Findings highlight the extent to which the progression of the disease impacts the everyday occupations of PD dyads, and how their worries and concerns influence their participation in exercise.

Table of Contents

List of Tables

List of Figures

Supplemental Materials

Abbreviations

IPD – Individual with Parkinson disease

PD – Parkinson disease

CG – spousal caregiver

QOL – Quality of life

SRM – Self-report measure

ADL – Activities of daily living

IADL – Instrumental activities of daily living

MDS-UPDRS – Movement Disorder Society – Unified Parkinson’s Disease Rating Scale

PA – Physical activity (used interchangeably with exercise)

RCT – Randomized controlled trial

MDS – Movement Disorders Society

SCT – Social Cognitive Theory

COPM – Canadian Occupational Performance Measure

Introduction

1.1 Synopsis

For individuals living with Parkinson disease (PD), exercise has been shown to be a beneficial adjunct treatment to address motor and non-motor symptoms (Fox et al., 2018; Goodwin et al., 2008). However, exercise intervention research has largely overlooked two critically underserved groups, namely family caregivers and the care dyad, as a unit. Given the progression of PD and the caregiving demands of the disease, the barriers to participating in exercise may be too difficult for many care dyads to overcome. For individuals with PD (IPD), research has focused on identifying and addressing the barriers that preclude exercise engagement (Ellis et al., 2013; Schootemeijer et al., 2020). For PD family caregivers, a paucity of studies tried to parse out how their disease-specific caregiving responsibilities create barriers to exercise (Pretzer-Aboff et al., 2009; Prieto et al., 2021). Moreover, it is not well understood how individual barriers and facilitators may influence both members of a PD care dyad to engage in exercise. The theoretical model of interdependence and communal coping provides a useful framework for gaining insight into the interpersonal and intrapersonal factors that influence a health behavior change (Lewis et al., 2006), such as the dyad's exercise participation, especially when faced with the health threat of PD. This study will focus on factors that may predispose the dyads to engage in exercise, namely the impact of daily occupations in the context of PD and caregiving, the dyads' worries and concerns about the progression of the disease, and the actions and behavioral changes made by the dyads to address those concerns. To that end, the selected research questions explore how the progression of PD and the perception of it as a threat to the health and well-being of the care dyad influences participation in exercise.

1.2 Overview of the Problem

As many as one million people in the U.S. are affected by PD (Marras et al., 2018). PD is a chronic, progressive neurological disorder characterized by motor symptoms of bradykinesia, rigidity, tremor, and postural instability (Weintraub et al,, 2008a), as well as non-motor symptoms including, but not limited to mood and sleep disorders, changes in cognition, urogenital dysfunction, and pain (Weintraub et al., 2008c). Progression of the disease is often classified by stages, such that early stages are differentiated by unilateral then bilateral involvement, followed by postural instability at mid-stage, then severe disability and incapacitation at late stages (Hoehn & Yahr, 1967). Disease progression and symptom presentation is heterogenous between IPD and is often quantified using the Movement Disorder Society-sponsored Unified Parkinson's Disease Rating Scale (MDS-UPDRS) (Goetz et al., 2008) with higher scores signifying greater motor and non-motor symptom severity. With worsening symptoms and disease progression, the ability to participate in and perform daily occupations, including activities of daily living (ADLs) are increasingly compromised (Chrischilles et al., 1998), resulting in loss of independent function (Shulman et al., 2008), and ultimately, diminished health-related quality of life (QOL) (Soh et al., 2013) as well as an increased reliance on family caregivers (Carter et al., 1998).

The advancing nature of the disease not only negatively affects individuals with PD, but increasingly and progressively affects their care partners. PD family caregivers, many of whom are spouses, provide a substantial portion of the care as part of their own daily occupations (Goy et al., 2008; Hand et al., 2016; Mosley et al., 2017), including assisting with ADLs and instrumental ADLs (Shin & Habermann, 2020). The care provided by PD family caregivers often comes at a cost to their own well-being with many reporting diminished physical and mental health (Schrag et al., 2006), decreased occupational participation (Lokk, 2009), and lower quality of life (Martinez-Martin et al., 2012).

It is essential to develop interventions that improve the health and well-being of both members of PD care dyads. While not a "fix-all" solution, exercise when coupled with standard clinical care has repeatedly been found to be beneficial for individuals with PD to remediate some motor (Fox et al., 2018; Goodwin et al., 2008) and non-motor symptoms (Cusso et al., 2016), improve occupational participation and performance (Foster et al., 2014), and address QOL (Rafferty et al., 2017). Despite the known benefits of exercise, many IPDs report a variety of barriers to participating, including general health and PD-specific symptoms, lack of time, low expectations for deriving benefits, fear of falling, diminished self-efficacy and other personal factors (Schootemeijer et al., 2020), to name but a few.

As for PD caregivers, exercise as a focused treatment and intervention to improve their health and well-being has received limited attention (Boone et al., 2021), largely because most PD-related interventions are focused on the IPD with the caregiver considered secondarily (Martinez-Martin et al., 2012), if at all. As such, it is not well known whether PD caregivers are willing and able to participate in exercise interventions tailored to their needs and focused on improving outcomes for them, specifically. However, a review of physical activity studies for caregivers, in general, suggested favorable effects on burden, and psychosocial outcomes, including QOL and well-being; but results were less robust for physical health (Lambert et al., 2016). Little has been reported on exercise and occupational participation and performance for PD caregivers; but one review of two occupational therapy-based exercise interventions noted improvements in occupational participation (Boone et al., 2021). Unfortunately, though, spousal caregivers across a variety of disease pathologies cite barriers to exercise, including their own health and well-being, lack of time, and increased fatigue (Castro et al., 2007), as well as feeling overwhelmed, and an inability to leave their care recipients due to an absence of support (Cuthbert et al., 2017; Janevic & Connell, 2004; Malthouse & Fox, 2014).

Dyadic interventions may provide opportunities for both the IPD and the caregiver to improve their health and overcome some barriers to exercise. Spouses and significant others can mutually influence mental and physical health, (Meyler et al., 2007), as well as the adoption of preventative health behaviors (Falba & Sindelar, 2008; Meyler et al., 2007; Pai et al., 2010). A systematic review of exercise interventions for older adult care dyads, conducted prior to the current study (Appendix A), found caregivers and care recipients may improve both psychosocial and physical health when exercising together (Doyle et al., 2021). Regrettably, though, no exercise studies on PD care dyads met the inclusion criteria for the Doyle et al. (2021) review, because the studies were not well-designed to address caregiver outcomes. What is known is that regular exercise has been shown to improve quality of life, and physical function for the individual with PD, while subsequently lessening caregiver burden (Oguh et al., 2014). However, in the Oguh et al. (2014) paper, the emphasis was on the IPD exercising, with caregiver burden measured as a co-variate. In a handful of dyadic exercise studies where IPDs were the focus of the treatment and experienced positive outcomes, the researchers offered primarily anecdotal and unvalidated self-reported measures as ambiguous evidence regarding the efficacy of dyadic exercise interventions for PD caregivers (DeCaro & Brown, 2016; Hackney & Earhart, 2010; Heiberger et al., 2011; Klein & Rivers, 2006).

In addition to the limited evidence on dyadic exercise interventions for PD care dyads, very little is known about the facilitators and barriers for them to participate in exercise. Interestingly, both IPDs and their family caregivers note the importance of the significant other regarding exercise participation. For IPDs, one of the more important facilitators of exercise is having a significant other to motivate them (Afshari et al., 2017; Schootemeijer et al., 2020). Similarly, many PD caregivers, report participating in at least one physical or social activity with their care recipients, and anecdotally indicate improved well-being (Prado et al., 2020).

To develop effective health interventions, including physical activity or exercise programs for PD dyads, it is important to base the programs on theoretical foundations (Painter et al., 2008). One theoretical approach that may lend support to furthering our knowledge of the barriers and facilitators for PD dyads to participate in exercise is interdependence theory with communal coping perspectives (Lewis et al., 2006). Lewis and colleagues (2006) proposed a model to better understand the effects of spousal influences on behavioral change, especially when the dyad is dealing with a health threat (Lewis et al., 2006). Specifically, when each member of the dyad is motivated to respond to the health threat for the benefit of both individuals and their relationship, they are more likely to engage in behavioral change.

The constructs of the model have been explored in behavioral research to understand how dyads engage in communal coping across a variety of diseases and health conditions affecting older adults (Basinger et al., 2021; Kamen & Darbes, 2018; Nissen et al., 2018). However, communal coping has been applied less frequently to understand the factors that underlie participation in physical activity by dyads facing diseases and chronic illnesses. A 2017 systematic review reported when at least one member of the dyad was at risk of a chronic illness, the dyad slightly increased physical activity, and made other positive health behavior changes (Arden-Close & McGrath, 2017). However, it is unclear from the Arden-Close and

McGrath (2017) review if any of the included studies actually applied the interdependence and communal coping theory. Also largely missing from the literature are theory-based examinations of communal coping and health interventions in dyads living with neurological conditions, including PD (Fakolade et al., 2020).

Overall, the ability for caregivers and care recipients to engage in leisure activities, like exercise is important to occupational participation (Kniepmann, 2014), and a vital aspect of occupational performance (Baum & Law, 1997). However, research is needed to advance the understanding of factors that influence PD care dyads to participate in physical activity with the goal of reducing barriers and developing exercise programs that improve physical and mental health, occupational participation and performance, and quality of life.

1.3 Research Question and Study Aims

This study was informed by the interdependence and communal coping model, which was developed to understand the effects of spousal and partner influences on behavioral change, when the dyad is confronted with a health threat (Lewis et al., 2006). To that end, we explored the following research question for this dissertation project: “How does the progression of Parkinson disease and the perception of it as a threat to the health and well-being of PD care dyads influence occupational participation in exercise?” The primary goal of this exploratory descriptive qualitative study was to conduct semi-structured interviews via web conference or telephone with PD care dyads. Additionally, the interviews were supplemented by descriptive quantitative data derived from self-report measures. The specific aims of this study were the following:

Specific Aim 1

Conduct an exploratory qualitative study using semi-structured interviews of dyads of individuals with PD and their family caregivers. Caregivers and care recipients were interviewed separately. Interview topics, framed by the theory of interdependence and communal coping, examined 1) daily occupations in the context of PD and caregiving, 2) worries and concerns about the progression of PD, 3) actions taken to address concerns, and 4) whether the former three topics affected participation in exercise. Themes were extracted that addressed the research question.

Specific Aim 2

Examine quantitative self-report measures of disease progression, health conditions, problems in occupational performance, quality of life, and participation in exercise. Findings were descriptively compared with the themes derived from the semi-structured interviews.

These aims addressed a critical gap in the care of individuals with PD and their caregivers, both as individuals and as a dyad, and examined a population that is largely underserved by clinical care and research focused on physical activity and exercise. Applying the theoretical constructs of interdependence and communal coping, this study examined dyadic factors influencing behavioral change, namely participation in exercise. Employing the more adaptive exploratory descriptive approach fostered an understanding of the experiences of both individuals in the PD care dyad, and how and why those experiences affected their daily occupations (Bradshaw et al., 2017). The information gleaned will be instrumental to hypothesis generation for future studies, possibly entailing a mixed methods approach to develop family-centered physical activity interventions for PD care dyads.

Background and Significance

2.1 Progression of Parkinson Disease: Effects on Health, Occupation & Quality of Life

2.1.1 Impact on Individuals with PD

In the U.S., approximately one million people—or 1% of the population of individuals above age 60—are affected by Parkinson disease (PD) (Marras et al., 2018; Tysnes & Storstein, 2017), which is a chronic, insidious neurological disorder characterized by both motor and non-motor symptoms. Diagnosis occurs when an individual develops three or more of the cardinal symptoms of bradykinesia, rigidity, tremor, and postural instability (Weintraub et al., 2008a). Motor complications are accompanied by non-motor symptoms including, but not limited to apathy, autonomic nervous system dysfunction, cognitive decline, depression and anxiety, compulsive behaviors, sleep disturbances, delusions, hallucinations, and psychosis (Chaudhuri & Schapira, 2009; Weintraub et al., 2008c).

Although every individual with PD experiences the disease in different ways, the progression of PD motor symptoms is typically characterized in five stages from mild to severe as classified by Hoehn & Yahr (Hoehn & Yahr, 1967). In stage one of the H&Y scale, individuals present with motor symptoms on one side of the body only and may have little to no impairments in function. At stage two, symptoms present bilaterally with mild functional impairments. At stage three, postural instability typically develops, and is the cause of increased occurrences of falls, gait disturbances and hip fractures (Boonstra et al., 2008). Stage four is the point at which the disease becomes severely disabling such that the individual requires considerable assistance with daily living; and in stage five, the individual is incapacitated and often bedridden or confined to a wheelchair. Though the H&Y scale is widely used as a simplified means of classifying disease progression, it does not account for the varying trajectories experienced by individuals, nor does it encompass the non-motor symptoms of the disease. Motor and non-motor features of PD as well as severity of symptom presentation relative to specific anatomical and functional considerations can be examined using the more comprehensive Movement Disorder Society-sponsored Unified Parkinson's Disease Rating Scale (MDS-UPDRS) (Goetz et al., 2008). The MDS-UPDRS is broken into four sections, each of which focuses on different characteristics of the disease. Part I: Non-Motor Aspects of Experiences of Daily Living, has two components, the first is a clinician/researcher delivered questionnaire with six questions that are asked of the individual with PD, the caregiver or both. The second component of Part I is a questionnaire given to the IPD, CG or the dyad and they are asked to circle the response that best fits the question. "Part II: Motor Aspects of Experiences of Daily Living" continues with thirteen more questions that are completed by the IPD, CG or the dyad. "Part III: Motor Examination" is administered by a trained clinical rater and uses a series of motor skill tasks to assess motor symptoms in different anatomical regions (hands and feet) and across a series of motor functions (walking and maintaining balance). Finally, "Part IV: Motor Complications" examines features of the individual's disease presentation to assess additional motor complications that may be affecting the IPD, specifically dyskinesias, motor fluctuations and dystonia. Across all sections, higher scores signify greater motor and non-motor symptom severity. Although non-motor symptoms have not been found to follow the same course and progression as motor symptoms, individuals who experience worsening motor symptoms are more likely to see an increase in non-motor symptoms (Antonini et al., 2012).

As the motor and non-motor symptoms of the disease progress, daily occupations of IPDs are affected, including basic and instrumental ADLs (Hariz & Forsgren, 2011; Sperens et al., 2020), sleep (Comella, 2007; Tandberg et al., 1998), physical leisure activities (Tickle-Degnen et al., 2015), as well as outdoor and social activities (Martignoni et al., 2011; Tickle-Degnen et al., 2015). Motor symptoms have been linked to decrements in performance of basic ADLs, and non-motor symptoms to instrumental ADLs, with both affecting physical leisure and social activities (Tickle-Degnen et al., 2015). The ability to perform ADLs and IADLS—such as walking, dressing, housework, transferring in and out of bed, and traveling within the community—are increasingly compromised with disease progression, ultimately resulting in loss of independent function (Shulman et al., 2008). A cross-sectional study by Shulman et al. (2008) examined the relationship between disease severity and functional limitations, and reported that IPDs who acknowledged having difficulty with 0-1 ADL, but not needing assistance, were typically in H&Y

stage I. By the time IPDs transition from H&Y stage II to III, and begin to experience postural instability, problems with gait, as well as activities involving gait, they typically report having difficulty with 2-6 ADLs and needing help with more than one, which equates to loss of independent function. When the disease progresses to stage III and beyond, IPDs report having trouble with 8 ADLs and needing assistance with 4 ADLs. Similarly, a 1998 and a 2020 study both found that as PD advances, patients experience more functional impairments, (Chrischilles et al., 1998), as well as self-reported decrements in ADL performance across several domains, including eating and drinking, mobility, toileting, dressing, personal hygiene, communication, cooking, and shopping (Sperens et al., 2020).

In parallel with the effects of PD progression on occupational participation, quality of life (QOL) diminishes with increasing disease severity (Schrag et al., 2000; Soh et al., 2013). Activity limitations in self-care and mobility, as well as fall history have been linked to poor health-related QOL (Soh et al., 2013). Another study also reported that decrements in mobility, such as the inability to get up out of a chair and freezing of gait were strongly correlated to occupational participation and diminished QOL in IPDs (Duncan & Earhart, 2011). Interestingly, several studies reported that non-motor symptoms have a greater impact on health-related QOL and well-being than motor symptoms (Martinez-Martin et al., 2011; Muller et al., 2013; Prakash et al., 2016). In a widely cited cross-sectional study, conducted with a large sample of international patients, authors reported that the presence of non-motor symptoms were the best predictor of poor QOL, and the most reported non-motor symptoms were sleep disturbances, namely nocturia and fatigue, as well as drooling (Martinez-Martin et al., 2011). Echoing the results of Martinez-Martin et al. (2011), a cross-sectional study conducted by Duncan et al. (2014), noted that non-motor symptoms related to mood disorders, decreased cognition, urogenital dysfunction, and sleep disturbances had the greatest effects on health-related QOL (G. W. Duncan et al., 2014). Taken together, PD progression equates to aggregating symptoms and functional impairments, which affect daily occupations, resulting in loss of independence and decreased health-related QOL for IPDs, which ultimately leads to a progressive increase in reliance on their caregivers.

2.1.2 Impact on Spousal and Family Caregivers

Providing a vital and significant portion of the care to the nearly one million individuals with PD (Hand et al., 2016; Mosley et al., 2017) are their family members, the majority of whom are spouses (Goy et al., 2008; Hand et al., 2016; Mosley et al., 2017). In general, spouses and partners (hereafter referred to collectively as spouses)—whether caregiving for PD or another progressive disease or chronic condition—typically provide more hours of care weekly (Pinquart & Sorensen, 2011), and feel a greater sense of obligation to be carers (NAC & AARP, 2015; Riffin et al., 2017; Wolff et al., 2016). Undoubtedly, caregiving requirements vary across the variety of pathologies affecting older adults. However, for caregivers whose care recipients have been diagnosed with progressive, incurable diseases, like PD, caregiving may become increasingly challenging. According to a secondary analysis of the data from the *Caregiving in the U.S. 2015* report (NAC & AARP, 2015), PD caregivers provide an average of six years of care for 28 hours weekly, with the hours and demands intensifying as their loved ones' disease progresses (Shin & Habermann, 2020).

Among the increasing demands and challenges of providing care are the additional occupations and activities that PD caregivers take on as their loved ones become more reliant on their assistance. A 1998 longitudinal study reported that on average, PD caregivers were undertaking 11-12 out of 51 caregiving occupations when their IPDs were in H&Y stages I and II; but the number of occupations doubled to 22 by H&Y stage III, and then increased to 30 by late stages IV and V (Carter et al., 1998). The more recent secondary analysis conducted by Shin and Habermann (2020) reported specifically on the average number of daily occupations performed by PD caregivers for their care recipients and noted 2.85 basic ADLs and 4.72 instrumental ADLs. Among the most common of the basic and instrumental ADLs, Shin and Habermann (2020) noted that caregivers were assisting with mobility, dressing, toileting, and bathing, as well as transportation, shopping, meal preparation, medication management, and tasks related to household management—many of which were over and above the occupations that caregivers handled prior to their loved ones' PD diagnosis. To take on these extra ADLs, as well as other caregiving activities, many PD caregivers compromise their own occupational participation and performance, particularly in the domains of social, leisure, and productive occupations (Berger et al., 2019; Lokk, 2009). In a study by Lokk (2009), the authors reported that PD caregivers with longer care durations were most likely to experience diminished occupational participation. As many as 50% of PD caregivers sacrificed leisure and social activities; and over 80% had fewer opportunities to perform their own ADLs (Lokk, 2009).

The care provided by PD family caregivers often comes at a cost to their own well-being with many reporting diminished physical and mental health (Schrag et al., 2006), increased strain (Carter et al., 1998) and burden (Martinez-Martin et al., 2007), as well as declines in quality of life (Martinez-Martin et al., 2012). With increasing caregiving demands, as many as 50% of PD caregivers report depression; 40% indicate diminished physical health; and 33% have a chronic health condition themselves (Schrag et al., 2006). Often parallel to their loved ones' disease-related symptoms, PD caregivers experience poorer sleep quality (Happe et al., 2002), injuries from assisting with falls (Davey et al., 2004), more mood disorders, as well as diminished social support, and increased feelings of isolation (Roland et al., 2010). Concomitant with progression of PD symptoms, caregiver strain increases with hours of care provided, disease duration, falls, and many of the PD-related motor symptoms (Carter et al., 2008; Mosley et al., 2017; Schrag et al., 2006). The Carter et al. (1998) study examining the impact of disease progression on caregivers noted their strain increased significantly at the midway point between H&Y stages II and III. Caregiver burden also intensified significantly when PD care recipients experienced non-motor psychological symptoms (e.g. depression, anxiety, apathy, hallucinations) (Mosley et al., 2017), as well as the occurrence of mild cognitive impairment, dementia, and impulse control disorders (Leroi et al., 2012; Mosley et al., 2017).

Concomitant with decrements to their physical and mental health, and increased burden and strain, PD caregivers may be more likely to experience diminished health-related QOL (Goldsworthy & Knowles, 2008; Martinez-Martin et al., 2005). While the determinants and predictors of QOL are multi-factorial, a descriptive review of the general and PD caregiving literature by Martinez-Martin et al. (2012) noted health-related QOL in caregivers likely worsens with their loved ones' disease severity and duration, as well as with diminished functional abilities, increased falls, and the presentation of non-motor symptoms. Reflecting the findings of the review, a 2008 study found that lower QOL for PD caregivers was predicted by IPDs' behavioral problems and functional limitations to performing ADLs (Goldsworthy & Knowles, 2008). A 2012 cross-sectional study also reported QOL for PD caregivers was negatively influenced by their care recipients' impairments in mobility and cognition, in combination with the duration of care provided, as well as the caregivers' own health conditions, age, and gender (Morley et al., 2012). A more recent cross-sectional study indicated PD caregivers' diminished QOL, as it related to mental health and meaningful occupations—namely daily living, self-care and socializing—was positively correlated to their care recipient's mobility and non-motor symptoms (Henry et al., 2020). Taken together, the progression of PD increases the demands on PD caregivers, which impacts their daily occupations, affects their health, and contributes to greater strain and burden, ultimately affecting their QOL and well-being.

2.1.3 Effects of PD Progression on the Care Dyad

Although largely understudied, researchers are beginning to examine care dyads to gain a better understanding of the impact of different aspects of PD on the dyad, as a unit. Cross-sectional and qualitative studies have examined the effects of disease progression on the dyad. One of the earliest quantitative studies to approach PD dyads reported that having greater perceived control over disease symptoms was significantly related to IPD well-being and decreased caregiver burden (Wallhagen & Brod, 1997). A 2011 cross-sectional study found poorer self-reported health of IPDs was related to higher caregiver strain and worse emotional health (Peters et al., 2011). More recently, a cross-sectional study reported significant moderate to strong agreement between IPDs and CGs when they each assessed their own QOL and that of their partner (Balash et al., 2017). In another recent study, nearly 70% of participating PD dyads reported both members experienced sleep disturbances (Wade et al., 2021) with IPD sleep problems associated with exacerbated CG mental health and burden, and CG sleep disturbances correlated with IPD mental health and complications stemming from therapy.

Among the qualitative studies exploring dyadic influences in PD, one of the earliest used a phenomenological design that revealed themes on how married couples dealt with the disease diagnosis, the impact on each member of the couple as individuals and as a unit, and their use of resources and strategies to deal with PD (Hodgson et al., 2004). Two other qualitative studies conducted with PD dyads in advanced stages noted the progression of the disease brought about conflicting concerns between the caregiver and the IPD in regards to placement in long-term care facilities (Habermann & Shin, 2017), as well as in-home safety concerns stemming from the presentation of numerous symptoms (Horning et al., 2019). In summary, garnering perspectives from both members of a PD care dyad as individuals, and as a unit is essential to clinical practice and to the development of future interventions to improve their health, occupational participation, performance, and QOL.

2.2 Exercise as an Adjunct Treatment to Improve Health, Occupations & QOL

To enhance health and well-being outcomes for individuals with PD and their spousal caregivers, it is of critical importance to explore and develop interventions that intentionally address both members of the dyad. Physical activity and exercise interventions are one possible solution. According to Caspersen et al. (1985), “Physical activity is defined as any bodily movement produced by skeletal muscles resulting in energy expenditure; and exercise is a subset of physical activity that is planned, structured and repetitive to improve physical fitness” (Caspersen et al., 1985). The two terms will be used interchangeably hereafter. Exercise has proven effective for older adults improving their physical and mental health, functional and cognitive capabilities, and offering opportunities for social engagement (Bauman et al., 2016). The sections that follow will provide an overview of the literature on the benefits of exercise to health, effects on occupations and QOL, as well as the barriers to exercise for IPDs, their spousal caregivers, and care dyads.

2.2.1 Benefits, Barriers & Facilitators to Exercise for Individuals with PD

To date, there is no known cure for PD. As such, pharmacological treatments are the first course of action to remediate motor symptoms. Unfortunately, though, PD drugs come with a host of negative side effects, including exacerbation of some non-motor symptoms, diminished drug effectiveness after prolonged use, motor fluctuations, and dyskinesias (Weintraub et al., 2008a). Once advanced symptoms become unresponsive to pharmaceuticals, surgical treatments, such as deep brain stimulation and pallidotomy, are the next option; but these, too, come with mixed results and the potential for severe side effects (Weintraub et al., 2008b). Supplemental to traditional clinical treatments, physical activity is effective as an adjunct treatment to improve PD symptoms. Physical activity and exercise have repeatedly been found to be beneficial for individuals with PD to remediate some motor (Fox et al., 2018; Goodwin et al., 2008) and non-motor symptoms (Cusso et al., 2016), improve occupational participation and performance (Doucet et al., 2021; Foster et al., 2014), and enhance QOL (Rafferty et al., 2017).

An exponentially growing body of research conducted over the past two decades substantiates that exercise offers a variety of health benefits and attenuates motor symptoms for individuals with PD. Based on evidence from randomized control trials (RCTs) performed between 2004 and 2016, the Movement Disorder Society (MDS) upgraded their rating of physical therapy-based exercises (e.g. strength training, aerobics, and flexibility) to “clinically useful”, and exercise-based movement strategies (e.g. balance and strengthening exercises to reduce falls) and formalized patterned exercises (e.g. dance, tai chi, and yoga) to “possibly useful” (Fox et al., 2018; Fox et al., 2011). A small sample of the interventions reviewed by Fox et al. (2018) are included herein to reflect improvements in motor symptoms and physical health for IPDs. Among physical therapy-based interventions, a high-quality RCT found favorable effects in three cohorts, such that low- and high-intensity treadmill-based exercise improved gait speed and cardiovascular fitness, where resistance training with stretching improved strength (Shulman et al., 2013). A randomized cross-over trial employing movement strategy training evaluated challenging balance exercises to usual care; the active cohort saw reductions in fall rate and fear of falling, along with improvements to balance (Sparrow et al., 2016). Although patterned exercise interventions tend to have varied outcomes (Fox et al., 2018), a quasi-randomized pilot design compared modern dance methods to PD-specific exercises, and usual care; the dance cohort experienced greater improvements in mobility, balance, cognition, apathy, and depression (Hashimoto et al., 2015).

Interventions that examined physical activity with an occupational therapy (OT) lens have demonstrated improvements to ADLs, sleep, participation, and QOL. A 2021 systematic review of articles published between 2011-2018 concluded the strength of evidence for improving participation and performance in ADLs and sleep ranged from low to strong (Doucet et al., 2021). Again, a small sample of the interventions reviewed by Doucet et al. (2021) are included herein to reflect improvements in ADLs and sleep, as measured by predominantly self-report measures, as well as a few performance-based outcomes. Among the strong, high-quality evidence was a study also included in the MDS review conducted by Fox et al. (2018). The RCT compared non-specific physical therapy to a multidisciplinary program combining functional exercise, cognitive training, and OT to perform and modify basic ADLs (Monticone et al., 2015); the multi-disciplinary cohort saw significant improvements in motor function, balance, functional independence to perform basic ADLs, and QOL. A lower quality RCT comparing multimodal exercise to usual care noted significant improvements to self-reported IADLs and sleep in the active cohort (Nascimento et al., 2014). Though not included in the Doucet et al. (2021) review, two studies demonstrated significant improvements in activity and participation following an RCT comparing Argentine tango to usual care (Foster et al., 2013), and a more recent single arm pilot study of yoga combined with falls risk management (Hill et al., 2021). QOL is closely linked to participation in meaningful and valued occupations (Kornblau et al., 2020), such as exercise. A prospective longitudinal study using data from the National Parkinson Foundation Quality Improvement Initiative Registry (NPF-QII) (Okun et al., 2010) reported that IPDs who consistently exercised more than 2.5 hours weekly showed better QOL, as well as slower declines in health-related QOL and mobility (Oguh et al., 2014; Rafferty et al., 2017).

Despite the multitude of benefits of regular exercise, the prevalence of IPDs who participate in exercise is unknown. In the Oguh et al. (2014) report from the NPF-QII Registry, 44% of the sample population indicated they participate in exercise; however, the sample likely reflects a bias in that the National Parkinson Foundation focuses on exercise education. Moreover, many IPDs—both those who currently exercise, as well as those who do not—report a variety of barriers to participating in physical activity (Schootemeijer et al., 2020). Non-exercising IPDs typically indicate lack of time, fear of falling, low expectations for deriving benefits from physical activity, as well as diminished self-efficacy (Ellis et al., 2011; Schootemeijer et al., 2020). Other barriers typically reported by low-exercising IPDs include fatigue, mood disorders, and low motivation (Afshari et al., 2017). In contrast, both low and high-exercising IPDs revealed they were more likely to exercise if their neurologists recommended it, or if they had someone, like a personal trainer or a loved one, to motivate them to do it (Afshari et al., 2017).

2.2.2 Benefits, Barriers & Facilitators to Exercise for Caregivers

Interest in developing focused treatments and interventions to improve health and well-being in caregivers is growing. However, for PD caregivers, the evidence is primarily limited to education and psychotherapy (Mosley et al., 2017), while exercise for PD caregivers as a focused treatment to improve PD caregiver health and well-being has received limited attention (Boone et al., 2021). Studies that have addressed IPDs and CG have focused on the IPD with the caregiver considered secondarily (Martinez-Martin et al., 2012). As such, it is necessary to turn to the literature addressing older adults in a broader sense (not focused on PD) to gain an understanding of the possible health benefits to be derived by PD caregivers who participate in exercise.

Given that many caregivers are older adults (NAC & AARP, 2015), we can begin by examining the literature focused on older adults and exercise. Exercise has proven effective for older adults to improve their physical and mental health, functional and cognitive capabilities (Bauman et al., 2016), QOL, and occupational participation (Berger et al., 2018) with increased opportunities for social engagement (Bauman et al., 2016; Berger et al., 2018). Recent reviews of interventions targeted to and focused on a broad range of caregivers suggest physical activity has a favorable effect on some psychosocial outcomes, such as QOL, well-being, anxiety, depression, stress (Lambert et al., 2016; Loi et al., 2014), and burden (Lambert et al., 2016; Loi et al., 2014; Orgeta & Miranda-Castillo, 2014). Results showing improvements to physical health were less robust, but studies have demonstrated that caregivers can increase participation in physical activity (Lambert et al., 2016). None of the exercise interventions included in the aforementioned reviews were designed specifically for PD caregivers, nor did they examine occupational participation.

Given the many challenges and demands involved in providing care to a loved one with PD, caregivers may feel it is unreasonable to include exercise in their lives. As such, it is not well known whether PD caregivers are willing and able to participate in physical activity interventions. As noted earlier, PD caregivers are often over-looked in studies or clustered in with other caregivers, therefore, it is necessary to examine general caregiver participation in physical activity and exercise. Overall, spousal caregivers are less likely to engage in exercise (Beach et al., 2000; Burton et al., 1997) with as many as 60% reporting insufficient physical activity (Etkin et al., 2008). Among family caregivers, higher hour spouse caregivers are the least physically active (Burton et al., 1997), the least likely to participate in vigorous exercise (Jenkins et al., 2009), and have the lowest self-efficacy for exercise (Etkin et al., 2008). It has been suggested that even though caregivers do not engage in exercise, the activities associated with caregiving may indicate they do not get less physical activity than non-caregivers (Fredman et al., 2006). However, accelerometry data from older adult caregivers and non-caregivers indicated there were few differences in physical activity levels (Marquez et al., 2012). While it is possible that the tasks associated with caregiving are not well measured with accelerometry-based approaches, it is likely these findings indicate that caregivers could benefit from exercise interventions.

Unfortunately, spouse caregivers cite a number of barriers to physical activity and exercise. Again, it is necessary to turn to the literature on spousal caregivers, in general, given the paucity of information available on PD caregivers, specifically. Among the barriers noted across a broad spectrum of spouse caregivers, barriers to exercise include their own mental and physical health (Cao et al., 2010; Etkin et al., 2008; Hirano et al., 2011; Marquez et al., 2012), perceptions of increased burden due to caregiving demands (Hirano et al., 2011), limited time to engage in their own self-care, and decreased self-efficacy (Etkin et al., 2008). Furthermore, spousal caregivers note that the most significant barriers to exercise include lack of time and increased fatigue (Cao et al., 2010; Castro et al., 2007). Other barriers noted by caregivers include a feeling of being overwhelmed, having a sense of guilt, and an inability to leave their care recipients due to an absence of support (Cuthbert et al., 2017; Janevic & Connell, 2004; Malthouse & Fox, 2014). Interestingly, some spouse caregivers indicate they do not enjoy exercising alone (Cao et al., 2010). A qualitative study found that psychosocial support was an especially important factor in influencing caregiver engagement and adherence to physical activity (Janevic & Connell, 2004).

Similar findings were echoed in a recent mixed methods study conducted specifically for PD caregivers to examine the influence of participating in a psychosocial intervention entailing dance, both with and without their care recipients (Prado et al., 2020). From the overarching themes of the qualitative interviews conducted by Prado et al. (2020), caregivers noted they strived for balance between their caregiving responsibilities and needs and activities for themselves. When these caregivers chose not to co-participate in dance and other activities with their IPDs, they chiefly cited the desire to reserve time for themselves, while insisting on independence for the IPDs. However, for the 62% of PD caregivers in the Prado et al. (2020) cohort who did co-participate, they noted the value of socializing with their spouse and others who were living with similar circumstances, and that the time spent dancing together offered a distraction from daily caregiving demands. Outside of research, many PD caregivers report participating in at least one physical or social activity with their care recipients, and anecdotally indicate improved well-being (Prado et al., 2020). Given that many caregivers are interested in co-participating in physical activity with their IPDs, research is needed to better understand and advance the development of PA programs to increase benefits and to reduce barriers for both members of PD care dyads to participate in such programs.

2.3 Dyadic Exercise to Improve Well-Being in PD Care Dyads

By involving both the care recipient and caregiver, dyadic interventions may overcome some barriers to engaging in physical activity, while benefitting both partners. Moreover, dyadic interventions may provide an opportunity for individuals with PD and their spouses to respond to the health threat of PD with a shared focus and co-opted sense of ownership. Here again, though, little information is available specifically on dyadic exercise for PD caregivers and care recipients. As such, it is necessary to review literature on dyadic interventions involving physical activity.

2.3.1 Dyadic Interventions May Capitalize on Spousal Influences

Marital and other close relationships have been linked to improved health outcomes, increased longevity, and adoption of healthy behaviors, especially in better quality relationships (Kiecolt-Glaser & Newton, 2001). Spouses can mutually influence mental and physical health, including perceptions of well-being and quality of life, development of depression, hypertension, and cardiovascular disease (Meyler et al., 2007), but also the adoption of preventative health behaviors (Falba & Sindelar, 2008; Meyler et al., 2007; Pai et al., 2010). Even though disease and functional limitations predict decreases in physical activity among older adult care recipients and caregivers (Li et al., 2013; Monin et al., 2016), positive correlations between spousal levels of physical activity and changes in exercise behavior suggest that if one spouse adopts or maintains exercise, the partner is likely to do so, as well (Cobb et al., 2016; Falba & Sindelar, 2008; Li et al., 2013; Pettee et al., 2006).

Dyadic interventions also have the potential to mitigate spousal caregivers’ restricted social participation (Baanders & Heijmans, 2007; Riffin et al., 2017; Wolff et al., 2016), and weakened relationships with friends, other relatives, and especially their spousal care recipients (Anton et al., 2013; Baanders & Heijmans, 2007; Davis et al., 2011). In fact, lower marital and relationship satisfaction has recently been linked to depression and poor health in caregiver-care recipient dyads (Monin et al., 2019). Similar findings have been reported in PD dyads;

however, when both members of the dyad express greater feelings of mutuality in the relationship, caregivers report less burden and their PD care recipients report diminished symptom severity; and both members of the dyad report less depression (Tanji et al., 2008). Interestingly, positive perceptions of exercise (Rauer & Hornbuckle, 2019), and exercising together (Yorgason et al., 2018) have been linked to better relationship quality and marital satisfaction in dyads of older adults.

Lending further support to the positive impact of dyadic interventions, a 2010 review and meta-analysis compared a range of couple-oriented to patient-only interventions. The authors included dyadic programs in which care recipients and caregivers either participated together or received treatments separately (Martire et al., 2010). For both types of dyadic interventions, 80% of studies yielded promising results for care recipients who experienced greater improvements in pain and depression, as well as marital relationships (Martire et al., 2010). In contrast, only 25% of the reviewed studies indicated similar improvements to caregiver well-being and relationships. The remaining studies either found no significant difference (30%) or did not report on caregiver outcomes (45%) (Martire et al., 2010). Among the key recommendations from Martire et al. (2010), the authors emphasized the importance of basing interventions on dyadic theoretical constructs, examining marital and spousal factors to better understand results, and most importantly, measuring outcomes in both members of the dyad.

2.3.2 Limited Evidence to Support Benefits of Dyadic Exercise

Of the included studies in the aforementioned Martire et al. (2010) review of interventions for couples, only three were exercise or PA studies; and only one reported outcomes for both care recipients and caregivers (Badger et al., 2007). Within the latter study reporting measures on both members of the dyad (Badger et al., 2007), care recipients with breast cancer and their spouses saw improvements to psychosocial well-being following participation in all three cohorts of the study, namely a telephone counseling program, a walking program, and an attention control group. A 2016 review of physical activity interventions primarily aimed at caregivers (Lambert et al., 2016), reported on two dyadic studies of multi-functional exercise for dementia care partners that found enhanced functional capabilities in care recipients was significantly related to decreased caregiver suffering and burden (Canonici et al., 2012), as well as better health-related QOL in caregivers (Marsden et al., 2012). Although in one study, it was unclear if dementia caregivers were co-participating or receiving separate treatment (Canonici et al., 2012). In the other study, caregivers of individuals with stroke were co-participating, but the authors only reported descriptive statistics due to a small sample size (Marsden et al., 2012). Another 2017 review of dyadic exercise interventions for dementia care partners supported some favorable health outcomes for both members of the dyad (Lamotte et al., 2017). However, the review included just four studies; and only two assessed functional abilities in care recipients, who experienced improvements following the multi-functional program already noted (Canonici et al., 2012) and a home-based exercise program for individuals with dementia (Ohman et al., 2016; Pitkala et al., 2013). Similarly, only three studies assessed caregivers for changes in burden (Canonici et al., 2012; Lowery et al., 2014; Prick et al., 2015), two of which found improvements following multi-functional exercise for care recipients (Canonici et al., 2012), and an individually tailored walking program for the dyad (Lowery et al., 2014). Whereas the other multi-component program with exercise for both members of the dyad found no significant difference, most likely due to low caregiver adherence to the exercise program (Prick et al., 2011). Authors of the Lamotte et al. (2017) review suggested there is a need for well-designed RCTs of dyadic interventions to better understand the effects of exercise on both dementia care partners.

2.3.3 Systematic Review to Parse Out Caregiver Outcomes from Dyadic Exercise

Given the heavy emphasis on care recipients in exercise interventions combined with the limited evidence available on dyadic exercise, especially for caregiver outcomes, I conducted a systematic review which was recently published (Doyle et al., 2021) in *The Gerontologist* (Appendix A). Unlike the previously mentioned systematic reviews, our study was specifically interested in identifying and examining caregiver outcomes following dyadic exercise. In particular, we explored whether caregivers, who are enrolled with their care recipients in a dyadic exercise intervention, derive greater physical and psychosocial health and well-being benefits when they co-participate in exercise, when their care recipient exercises independently while the CG receives another non-exercise treatment, or when the CG continues with usual care. The review is one of the first to directly compare the two types of dyadic interventions. Of the 4,951 studies reviewed, only eleven studies met inclusion criteria. Included studies were fair to good quality with moderate to high risk of bias. In six of the included studies, the dyad exercised; in five, care recipients exercised while caregivers received a separate program, or usual care.

Results suggest caregivers may improve both psychosocial and physical health when exercising together with care recipients. Caregivers, who did not exercise but received a separate, non-exercise intervention, such as support, education, or respite, showed psychosocial benefits only. Those who received usual care were less likely to derive either physical or psychosocial benefits. In general, spousal and family caregivers may gain more from engaging in dyadic exercise compared to when their care recipients exercise independently. Given that the focus was primarily on caregivers, we predominantly reported outcomes for care recipients in the evidence tables. To summarize, though, care recipients experienced mixed outcomes, but they did see beneficial effects in varying indicators of psychosocial, physical, and functional well-being across the two types of dyadic exercise interventions, namely those in which they co-participated with their caregivers and those in which they exercised independently.

Several overall conclusions and recommendations came out of the Doyle et al. (2021) review. Firstly, exercising together may be more beneficial to both members of a care dyad. For interventions focused on care recipients, it may be particularly advantageous to include a separate treatment for care partners. Secondly, more RCTs and rigorous methodologies are needed, because nearly 100 studies that made it to the final review stage were excluded due to methods that were not well-designed to include caregivers or address their outcomes. Many of these studies included only single questionnaire data points from the CGs without any additional contextual information or even simple demographic data. In many cases, the "intervention" for the CG was either not well described or lacked the necessary information to allow for study replication. Thirdly, and of critical importance, it is essential to gain a greater understanding of the interests and needs of caregivers and care recipients through qualitative and quantitative approaches, including assessments to interview and survey both members of the dyad to inform and develop family-centered interventions.

2.3.4 PD Specific Dyadic Exercise Studies

Sparse evidence exists to ascertain the efficacy of exercise interventions for dyads of caregivers and IPDs. As noted in an earlier section of this chapter, a growing body of research substantiates that exercise, as an adjunct treatment for individuals with PD, is likely efficacious and "possibly useful" for remediating motor symptoms (Fox et al., 2018), improving cognition (Seppi et al., 2019), and offering a variety of health benefits (Goodwin et al., 2008). As for PD caregivers, two of the three previously cited systematic reviews and meta-analyses did not include caregiver outcomes (Fox et al., 2018; Goodwin et al., 2008); and the third only mentioned caregivers as being an important resource for reporting on the development of compulsive disorders in their PD care recipients (Seppi et al., 2019). However, data from the National Parkinson Foundation QII Registry (Okun et al., 2010) did indicate that regular exercisers with PD had less severe symptoms with better physical function and quality of life; and their caregivers indicated diminished burden (Oguh et al., 2014).

In contrast to Oguh et al. (2014), a critical review of interventions that measured PD caregiver burden concluded that dyadic multi-disciplinary treatments involving physical activity, which was targeted only to individuals with PD demonstrated no improvements in burden or quality of life for their caregivers, who did not co-participate in the exercise (Mosley et al., 2017). Similarly, an individually-tailored, multi-disciplinary treatment program for PD care recipients included two caregiver support group sessions; however researchers reported no significant differences in anxiety, depression or quality of life for the caregivers (Trend et al., 2002). Although not an exercise study, an in-home dyadic occupational therapy intervention targeted PD care recipients, and offered information and skills training to caregivers

(Sturkenboom et al., 2014). While care recipients did improve in measures of occupational performance, the authors did not measure it in caregivers and also found no significant improvements in psychosocial well-being, or decreases in daily minutes of care provided. Quality of life, however, did show a small, but significant improvement (Sturkenboom et al., 2014).

Similarly, interventions in which PD caregivers co-participated are limited in number and have returned mixed feedback. Tango dance interventions, in which PD dyads are typically encouraged to co-participate, have yielded mixed reports. A case study involving an elderly individual with severely advanced PD showed improvements in balance, gait, and quality of life following tango; but his caregiver spouse reported significantly increased burden (Hackney & Earhart, 2010). In contrast, caregivers who were invited to co-participate in tango dance with their care recipients provided anecdotal reports of improved well-being (Heiberger et al., 2011). Similar anecdotal improvements were reported in the well-being of co-participating PD dyads following a single bout of Laughter Yoga; however, the assessment tool was the unvalidated Laughter Yoga "How Do You Feel?" questionnaire (DeCaro & Brown, 2016). Another yoga study, primarily designed for IPDs, included four CGs who were assessed for changes in psychosocial outcomes (Walter, 2019). Although mean change scores indicated improvements, caregivers were only asked retrospectively to provide pre-test and post-test responses to self-report measures. More recently, a pilot educational study, offered a dyadic program to help IPDs and caregivers learn to self-manage PD through a variety of approaches including medication management, meeting physical activity recommendations, encouragement to engage in exercise, and more (Lyons et al., 2019). While not an exercise intervention, the Lyons et al. (2019) study demonstrated caregiving spouses were able to significantly engage in mental relaxation techniques, but no other outcomes were statistically significant. While the effect sizes were small, IPDs increased their aerobic activity and practices of mental relaxation; whereas caregivers improved participation in strengthening activities, and saw improvements to depression and self-efficacy; both members of the dyad improved their use of techniques to moderate negative feelings about PD.

Despite the equivocal evidence coming from interventions in which both members of a PD dyad are involved, either as co-participants in the same program or as participants in separate treatment programs, qualitative studies are yielding important information about the perceived value of dyadic interventions for IPDs and their spouse caregivers. For example, a study of taiji for IPDs and their support partners revealed themes that both members of the dyad experienced psychosocial and physical benefits, with balance being the most-often cited physical benefit (Klein & Rivers, 2006). While the quantitative outcomes for balance, functional mobility, and quality of life did not yield significant results, this may be partially attributed to the small subset of participants who agreed to complete the tests. Another more recently published qualitative study of PD dyads who had co-participated in a community dance program reported they were both motivated to find ways for the IPD "to keep moving" to ameliorate the impact of PD (Prieto et al., 2021). For their caregivers, that impetus translated to providing "compassionate support" by facilitating the participation of their IPDs in social and physical activity interventions through the provision of transportation, being in class to offer encouragement and physical assistance, and to enhance the relationship with their loved ones. PD dyads also reported on their perceived benefits of participating in the community dance program, including improved feelings of independence and acceptance of mobility limitations, being part of an understanding and welcoming community of others living with PD, and improved functional capabilities and flexibility. The Prieto et al. (2021) study also explored barriers to participation in the community dance program and noted the main barriers for both members of the PD dyads were their health comorbidities, but also weather conditions brought on by seasonal changes. Given the themes derived from the Prieto et al. (2021) study, it demonstrates the importance of conducting dyadic interventions in which IPDs and their care partners co-participate. Moreover, it lends further support to the relevance of exploring how living with PD influences dyads to engage in physical activity interventions, as a means to improving health, occupational participation, quality of life, and overall well-being.

2.4 Interdependence Model of Communal Coping for Couples

To develop effective health interventions, including physical activity or exercise programs for PD dyads, it is important to base the programs on theoretical foundations (Painter et al., 2008). One theoretical approach that may lend support to furthering our knowledge of the barriers and facilitators for PD dyads to participate in exercise is the interdependence model of communal coping for couples (Lewis et al., 2006).

2.4.1 Overview of the Theory

Lewis and colleagues (2006) proposed a model combining interdependence theory and communal coping perspectives to understand the effects of spousal influences on behavioral change, especially when the dyad is dealing with a health threat (Lewis et al., 2006). (See Figure 1.) Interdependence describes the way each partner in a dyad influences the relationship, interactions, and behaviors through intrapersonal effects (self effects), interpersonal effects (partner effects), and joint effects (Lewis et al., 2006; Rusbult & Van Lange, 2003). The interplay of these effects shapes how the dyad responds when one partner is confronted with a health threat, such as PD. According to Lewis et al. (2006), if both partners transform their motivation from consideration of self to consideration of the affected partner or the relationship, then a communal coping response—a shared meaning of the threat, and belief that they can meet the challenge together—may occur and thus elicit behavioral change.

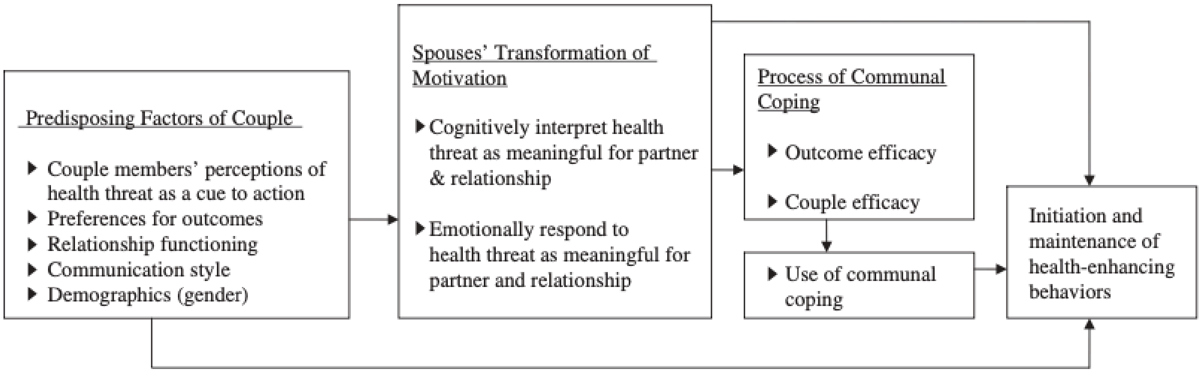

Figure 1. Interdependence model of couple communal coping and behavior change (Lewis et al., 2006).

Affecting the dyad's transformation of motivation and likelihood of engaging in communal coping are what Lewis et al. (2006) refers to as predisposing factors, such as how strongly and similarly the couple perceives the health threat, whether they agree on the need for behavioral change and expected outcomes to control or cure the threat, if their relationship quality is good, and if their communication with each other is positive and bi-directional. Gender can also play a role in communal coping. Men are more likely to rely on their spouses for support when facing a health threat; whereas women are more likely to try changing their partners' behaviors, but less likely to rely on a partner to avoid burdening the other person (Umberson et al., 2010). Couples who have transformed their motivation to engage in communal coping pursue mutual joint effects, in which the partners either work together to do the same thing or work together to do different things so that one partner can engage in the behavior. Or each partner does something different so that they can both engage in another behavior. When the partners pursue mutual joint effects, the dyad is more likely to initiate and maintain behavioral change.

2.4.2 Communal Coping for Dyads Living with Disease

Constructs of the interdependence model of communal coping have been explored in behavioral research to understand how dyads engage in communal coping across a variety of diseases and health conditions, including general chronic illnesses (Basinger et al., 2021), chronic musculoskeletal pain (Prenevost & Reme, 2017), coronary heart disease (Nissen et al., 2018), diabetes (Helgeson et al., 2019), heart failure (Wooldridge et al., 2019), human immunodeficiency virus (Montgomery et al., 2012), and prostate cancer (Kamen & Darbes, 2018), as well as other conditions. For example, a qualitative study of diabetic dyads examined how the diabetic partner’s perceptions of the disease as a threat to the individual’s well-being versus a shared threat to the couple was shown to influence whether the couple engaged in collaborative and supportive behaviors (Helgeson et al., 2019). Results of the Helgeson et al. (2019) study found that the partner of the individual with diabetes was more likely to view the health threat as shared; but when the diabetic partner also considered it a shared threat, the couple was more likely to facilitate collaboration and support. For those diabetic dyads, in which both partners viewed the threat as shared, support levels were highest, which was associated with better physical and mental health. A study conducted with dyads at risk for HIV transmission reported that transformation of motivation to engage in behavioral change (Montgomery et al., 2012), namely HIV prevention education, was more likely to occur when couples were recruited for participation in the program as a dyad, and when both members of the dyad felt they had something to gain from the intervention (Montgomery et al., 2012). For couples living with coronary heart disease (CHD), the diagnosis was found to be like a “slap in the face” and a “wake up call” (Nissen et al., 2018). Whether the couples responded to the threat of CHD with communal coping to make healthy lifestyle changes was based on the degree to which they shared their feelings, communicated openly, viewed the CHD diagnosis as an impact on their relationship and lifestyle, and whether the couple was willing to make mutually agreeable changes. Nissen et al. (2018) recommended that therapeutic interventions involving behavioral and lifestyle changes for individuals with a chronic health condition should consider not only the individual’s perspectives, but also interactions between the dyad to help reduce barriers to behavioral change.

2.4.3 Communal Coping to Understand Dyadic Exercise

Applied less frequently to physical activity, communal coping has started to gain traction in the last five years such that more researchers are citing the Lewis et al. (2006) model—though, not necessarily adhering to all its constructs. Overall, three systematic reviews referencing the Lewis et al. (2006) model reported small, but favorable effects of dyadic physical activity interventions to reduce sedentary behavior (Carr et al., 2019), increase physical activity (Arden-Close & McGrath, 2017; Richards et al., 2018), and make other positive health behavior changes when at least one member of the dyad was at risk of developing a chronic illness (Arden-Close & McGrath, 2017).

Among the studies included in the reviews, one intervention for older adults at risk of CHD and cancer, received educational materials in the mail encouraging participation in physical activity (Gellert et al., 2011). Individuals were more likely to engage in PA if their partners also exercised and provided social support. Another study found that dyads, in which one or both partners were obese and diabetic, increased their participation in PA and experienced significant weight loss when the couple participated together in a multi-component behavioral intervention (Wing et al., 1991). However, it is unclear from the two previously mentioned studies whether authors applied a theoretical approach, let alone the interdependence and communal coping model.

Among the communal coping and PA literature, was a qualitative study conducted with heart failure dyads (Wooldridge et al., 2019). Interestingly, participating dyads were more likely to view PA as the responsibility of the individual affected by the disease, rather than collaboratively engaging in exercise (Wooldridge et al., 2019). An additional study adhering to the interdependence and communal coping model, found that communal coping in dyads living with diabetes was positively associated with PA as a means of self-care; and that Blacks were more likely to employ PA for self-care than Whites (Basinger & Hartsell, 2020). In summation of this sampling of studies—either citing or employing the interdependence and communal coping model as applied to PA—it appears that positive effects have been observed for dyads who co-participated in physical activity. However, as noted in the Richards et al. (2018) review, the results were varied between interventions with effects typically realized over a limited and short period of time (Richards et al., 2018).

2.4.4 Limited Use of Communal Coping with PD Care Dyads

Largely missing from the literature are theory-based examinations of communal coping and health interventions in dyads living with neurological conditions, including PD (Fakolade et al., 2020). In a review by Fakolade et al. (2020), only three PD dyad studies met inclusion criteria for basing their interventions on theoretical constructs (Cash et al., 2016; Nelson et al., 2010; Sturkenboom et al., 2014). However, none of the three utilized the interdependence model of communal coping for couples. Instead, the only study to include outcome measures related to exercise was a study by Nelson et al. (2010), which examined the effects of a self-management program for veterans with PD and their spouses (Nelson et al., 2010). The intervention was based on the constructs of self-efficacy from social cognitive theory (SCT) (Bandura, 1977). Nelson et al. (2010) reported participants attained a small, but insignificant increase in the amount of time spent exercising; plus, they noted group support was important to continuing self-management skills. A second study of mindfulness training, also based on self-efficacy from SCT reported that mindfulness improved for all PD dyads, as did depression and language functioning for IPDs with a decrease in emotional and cognitive symptoms (Cash et al., 2016). The third PD-focused study, which was based on perceived competence from self-determination theory (Ryan & Deci, 2000) entailed a home-based intervention to provide customized occupational therapy (Sturkenboom et al., 2014). This latter study found that IPDs and caregivers reported a self-perceived improvement in daily activities. In general, it appears that basing interventions on theoretical foundations for PD dyads may be relevant to attaining beneficial results; however, the paucity of literature and physical activity studies for PD dyads that are based on theoretical foundations, including the interdependence and communal coping model, warrants further exploration.

2.5 Summary and Rationale for the Study

For individuals living with PD, exercise has been shown to be a beneficial adjunct treatment for improving motor and non-motor symptoms of the disease (Fox et al., 2018; Goodwin et al., 2008). However, exercise intervention research has largely overlooked two critically underserved groups, namely family caregivers and the care dyad, as a unit. Given the progression of PD and the caregiving demands of the disease, the barriers to participating in exercise may be too difficult for many care dyads to overcome. For individuals with PD, research has revealed a multiplicity of barriers that preclude their ability to engage in exercise (Ellis et al., 2013; Schootemeijer et al., 2020). For PD family caregivers, a paucity of studies has addressed how their disease-specific caregiving responsibilities create barriers to exercise (Pretzer-Aboff et al., 2009; Prieto et al., 2021). Moreover, it is not well understood how individual barriers and facilitators may influence both members of a PD care dyad to engage in exercise.

The theoretical model of interdependence and communal coping provides a useful framework for gaining insight into the interpersonal and intrapersonal factors that influence a health behavior change (Lewis et al., 2006), such as the dyad's exercise participation, especially when faced with the health threat of PD. This study will focus on factors that may predispose the dyads to engage in exercise, namely the impact of daily occupations in the context of PD and caregiving, the dyads' worries and concerns about the progression of the disease, and the actions and behavioral changes made by the dyads to address those concerns. To that end, the research question for this proposal explores how the progression of PD and the perception of it as a threat to the health and well-being of the care dyad influences participation in exercise.

The proposed study addresses a critical gap in the care of individuals with PD and their caregivers, both as individuals and as a dyad, and examines a population largely underserved by clinical care and research focused on physical activity and exercise. Applying the theoretical constructs of interdependence and communal coping, this study will examine dyadic factors influencing participation in exercise. Given the limited application of the theory in physical activity interventions for PD dyads to date, this study may prove useful in identifying additional factors influencing dyadic participation in exercise. Moreover, this study will help to shift research and clinical paradigms by including caregivers and examining the dyad as a unit. Caregivers are often overlooked for participation in exercise interventions or asked to mediate exercises for care recipients; yet caregiver outcomes are examined only secondarily, if at all. Including caregivers in future exercise interventions may increase the effectiveness for both members of the dyad to improve their health, occupational participation and performance, quality of life, and ultimately their well-being. To that end, this study qualitatively and quantitatively explored how spouses and family members can mutually influence mental and physical health, quality of life, occupational performance, and participation in exercise when faced with a health threat, such as PD.

Methodology

3.1 Study Design

We conducted a qualitative descriptive exploratory study (Bradshaw et al., 2017; Parse, 2001) to address the research question: For dyads of individuals with Parkinson disease (PD) and their family caregivers, how does the progression of PD and the perception of it as a threat to the health and well-being of the IPD and/or the dyad affect participation in exercise? Employing semi-structured interviews, we conducted web conferences with dyads of individuals with Parkinson disease (IPD) and their family caregivers. Additionally, the interviews were supplemented by descriptive quantitative data derived from self-report measures, which were mailed to each member of the dyad after the semi-structured interviews. The study was informed by the interdependence and communal coping model, which was developed to understand the effects of spousal and partner influences on behavioral change, when the dyad is confronted with a health threat (Lewis et al., 2006).

Rationale for selecting an exploratory study stemmed from the limited knowledge available in the literature to better understand how the progression of PD affects both members of PD care dyads and their participation in exercise. Additionally, the exploratory design afforded flexibility in adapting our qualitative instrument to better address our questions of interest. Although the results cannot be generalized to a broader population, the information derived from the exploratory study will lay the groundwork for generating hypotheses for the design and implementation of future studies.

This study was approved by the Education and Social/Behavioral Science IRB Office of the University of Wisconsin-Madison (protocol #2020-1054). Study methods and reporting are based on the COREQ Checklist, Consolidated Criteria for Reporting Qualitative Research (Tong, Sainsbury, & Craig, 2007) (See Appendix B for the COREQ Checklist).

3.2 Participants

A purposive sample of four dyads of individuals with PD and their primary family caregivers participated in this exploratory study. Given the exploratory nature of the study, an a priori determination was made to target four to six dyadic interviews. It was agreed that the total number of participants would be determined by the two primary mentors (SA and KP) of the study based upon saturation of themes and the extent to which the interviews were informing the implementation of the future study design. All interested participants initiated contact via phone or e-mail with the lab study team, who then conducted a pre-screening over the telephone prior to enrollment. The pre-screening included a brief description of the study, and questions to assess eligibility for enrollment. (See Appendix C for the pre-screening script and questions). Both members of the dyad had to meet inclusion criteria to participate. Once inclusion criteria were met, if one member of the dyad opted out of the study, the other member of the dyad was able to choose to continue participating, or opt out, as well.

3.2.1 Inclusion criteria

1. ***Both members of the dyad.*** To be included in the study, both members of the dyad had to: 1) reciprocally identify as either spouses, partners, adult child/parent, or other family members; 2) be at least 45 years old; 3) be English speaking; 4) be able to give informed consent; 5) agree to participate in the interview, and 6) complete and return self-report measures. Including individuals as young as 45 years of age enabled us to potentially capture care dyads living with young-onset PD.

2. ***Individuals with PD (IPD).*** Additionally, IPDs had to have a diagnosis of “probable PD” (E. B. Montgomery, Koller, et al., 2000; E. B. Montgomery, Lyons, & Koller, 2000) based upon established criteria (Calne, Snow, & Lee, 1992; Hughes, Daniel, Kilford, & Lees, 1992).

3. ***Caregivers***. To be included, caregivers had to be currently providing unpaid care or assistance to the person with "probable PD".

3.2.2 Exclusion criteria

Two main exclusion criteria were applied: 1) paid caregivers; and 2) care recipients with moderate to severe cognitive impairment, as indicated by a score of 3 or 4 on the MDS-UPDRS, part I, question 1 (Goetz et al., 2008).

3.2.3 Recruitment

Participants were recruited through the American Parkinson's Disease Association–Wisconsin (APDA-WI), Minnesota (APDA-MN), and the Waunakee Senior Center's PD support group, which together have contacts exceeding 5,000 households. All three organizations helped recruit for this study by either sending e-mails to their members, posting information on their websites, in print, other electronic communiqués, social media, and/or web conferences. (See Appendix D for recruitment materials.) No in-person recruiting, interviews, or form intake occurred due to safety precautions for COVID-19. Upon completion of the interviews and return of the self-report forms, each participating member of the dyad received a VISA gift card valued at $50.

3.2.4 Enrollment and consent

Once enrolled, the semi-structured interviews were scheduled for each member of the dyad and a paper copy of the consent form was mailed to each participant. (See Appendix E for the consent form). Following the protocol for a waiver of signed consent which was granted by the IRB, all participants provided verbal informed consent prior to participation. The consent discussion was completed over the phone or via video conference at the beginning of the semi-structured interview appointment.

3.3 Approach: Qualitative Outcomes using Semi-structured Interviews

3.3.1 Interviews & Interview Guides

Semi-structured interviews were conducted separately with each member of the participating dyads over video conference or telephone between December 2020 and June 2021. Interviews began with the lead interviewer reviewing and obtaining verbal consent. Following consent, the secondary interviewer (JSD) administered the Canadian Occupational Performance Measure (COPM) (Law et al., 1990). Once the COPM was completed, the lead interviewer conducted the remainder of the session. (See section 3.4.1 for a description and rationale for using the COPM.)

Using an interview guide developed around the theory of interdependence and communal coping (Lewis et al., 2006), the interview topics and probing questions focused on: 1) daily occupations in the context of PD and caregiving, 2) worries and concerns about the progression of PD, 3) actions taken to address concerns, and 4) whether the former three topics affect participation in exercise. Two variations of the guide, though similar in content, were used to tailor the questions to caregivers and IPDs. Each question had three parts asking the participant to focus on their own experiences, then the experiences of the partner, and the experiences of the two of them together. (See Table 1 below for a sampling of interview questions. See Appendix F for interview guides, which included additional topics relative to other aspects of the theory and will be analyzed in future studies.) To test readability and comprehension, interviews were pre-tested by five study team members with a general knowledge of PD, caregiving, and exercise for care dyads. Questions and probes were modified, and additional questions included based on feedback during testing and completion of the first few interviews.

Table 1. Sample questions and probes from the interview guides.

Constructs of Communal Coping	Caregiver	Individual with Parkinson Disease
Daily Occupations in the Context of PD and Caregiving	**Tell me what a typical day looks like for you and (*name of loved one*).**	**Tell me what a typical day looks like for you and (*name of loved one*).**
	What kinds of things do you do to help him/her every day? *(Probes: ADLs, hours per day providing help, physical assistance, doctor's appointments, driving, emotional and mental care)*	**How do your symptoms affect you on a daily basis?** *(Probes: ADLs, personal care, mobility, taking care of finances or things around the house, driving, physically, emotionally and mentally)*
	How does (*name – his/her*) PD and the things that you do to help him/her impact the things you personally want to do, need to do, or are expected to do every day? How does (*name – his/her*) PD affect the things the <u>two of you do together?</u> *(Probes: household activities, work/volunteer, leisure, social, self-care)*	**What kinds of things does your spouse/family member help you with every day? How do your symptoms affect the things the <u>two of you do together</u> –** *(Probes: ADLs, physical assistance, doctor's appointments, driving, emotional and mental care)*
Perception of PD as a Threat to the Individual and/or the Dyad	**What are your concerns or worries about your spouse or family member's PD symptoms?** *(Probes: Motor Sx, non-motor Sx, balance, falls, cognition, disease progression, hospitalization, institutionalization)*	**What are your concerns or worries about your PD symptoms?** *(Probes: Motor Sx, non-motor Sx, physical and mental health, balance, falls, ability to self-care, hospitalization)*
	How do your concerns about your spouse and his/her symptoms affect you personally? And how do your concerns or worries about PD affect the two of you together? *(physical and mental health, balance, falls, ability to continue providing care, time and ability to take care of yourself, hospitalization, social)*	**What are your spouse's/family member's concerns about your PD? How do your concerns or worries about PD affect the two of you together?** *(Probes: Motor Sx, non-motor Sx, physical and mental health, balance, falls, ability to self-care, hospitalization)*
Exercise as a Behavioral Change or Preventative Action	**We know that exercise is one way to improve health and well-being for caregivers.** Tell me about your personal interests and experiences with exercise. *(Probes: exercise in the past or currently; perceptions of exercise, benefits/detriments, if no exercise, why not?)*	**We know that exercise is one way to improve health and well-being for individuals with PD. Tell me about your personal interests and experiences with exercise.** *(exercise in the past or currently; perceptions of exercise, benefits/detriments, if no exercise, why not?)*
	What about exercising together with your spouse/family member? Tell me about those experiences and your interests. *(Probes: exercise in the past or currently, perceptions, barriers; if no exercise together, why not?*	**What about exercising together with your spouse/family member?** Tell me about those experiences and your interests. *(Probes: exercise in the past or currently, perceptions, barriers; if no exercise together, why not?)*
	Earlier you told me shared your worries and concerns about (your loved one's) PD, how does that affect your interest in having him/her exercise? And how do those affect your interest in and willingness to exercise yourself? Or exercising together?	**Earlier you shared your worries and concerns about your PD, how does that affect your interest in and willingness to exercise?** And how do those worries affect your interest in your spouse/care partner exercising? Or exercising together?

3.3.2 Setting & Data Collection

All interview sessions were conducted by two researchers—lead interviewer (KLD) and a secondary interviewer/note taker—in a private, closed-door office, via secure web conference platform for seven participants (Zoom Video Communications Inc., 2016) and by telephone for one IPD; all interviewees participated from their homes. Given the potential for sensitive topics to arise, where possible, the lead interviewer requested the caregiver and care recipient participate in the interviews separately and independently from each other to foster more candid responses. However, if it was not possible for them to participate independently, this was noted and recorded. One caregiver stayed in the room or in a room nearby during the IPD's interview. The duration of interviews was approximately 2½ to 3 hours for caregivers, and 1½ to 2½ hours for care recipients. All interview responses were audio recorded. Field notes were taken during interviews to record key impressions; then the study team debriefed immediately after each interview.

3.3.3 Research Team and Reflexivity

All semi-structured interviews were conducted by two female graduate students: one PhD candidate (KLD-lead), and one entry-level occupational therapy doctoral student (JDS-secondary). The PhD candidate had prior private industry experience in qualitative research with focus groups; and she had past involvement as a long-distance family caregiver to a parent with dementia, grandparents with chronic illnesses, and a Veteran spouse with service-related disabilities and post-traumatic stress disorder. Additionally, both the lead and secondary interviewers have had experience working with older adults, including caregivers in clinical settings and fitness facilities; and both have conducted quantitative research involving individuals with PD and older adults.

Both interviewers received coaching from two female members of the dissertation committee (SA, KP). SA has experience in qualitative research methods focused on developing and evaluating behavioral interventions for community members with chronic conditions living in rural settings. KP, as the principal investigator (PI) focuses on implementation of activity-based interventions, delivered in-home via telehealth to improve the everyday lives of older adults and people with PD.

For four interviews, rapport was easier to establish given that both interviewers had previously met the participating dyads either during assessments, telecycling sessions, and/or tango dance classes offered as part of the research and community outreach activities of the principal investigator (KP). Additionally, each interview began with the lead and secondary interviewers introducing themselves and giving a brief overview of their work in graduate school, and their personal interests in the study topic.

It should be noted all interviews took place during the COVID-19 pandemic. The extent to which the pandemic altered the outcomes of the interviews cannot be fully accounted for. Participants and interviewers had all experienced social isolation, disruptions to daily activities, pandemic related stress, and significant changes to support structures at the time of the interview sessions.

3.3.4 Qualitative Data Analysis

Audio recordings of interviews were first transcribed verbatim using NVivo Transcription (QSR International Pty Ltd., 2020), which is an automated service reporting up to 90% accuracy. The study team then reviewed, and quality checked each transcript by comparing them to the original audio recordings for completeness and accuracy. All files were de-identified.

Transcribed interviews were analyzed to identify underlying themes using open coding. Each transcript was initially reviewed and coded by two study team members to identify major themes and generate initial codes with definitions. Next, initial codes were reviewed, and a codebook was established by two data analysts using a standard iterative process similar to that of MacQueen et al. (1998). The resulting codebook had five parts for each code: 1) a category that served as a “broad definition” for each code; 2) a brief definition to jog the analyst’s memory; 3) a “full definition” that more fully explains the code; 4) a “when not to use” definition; and 5) an “example” section of quotes pulled from the data that were good representations of when and when not to apply the code (See Appendix G for the codebook).

In addition to reviewing the codes to identify frequency, patterns of responses, and reoccurring themes, the communal coping theory was used to guide the development of the themes related to the research question. The codebook was used to code all transcripts with frequent meetings among study team members to review codes and resolve discrepancies. After the study team agreed upon and defined the final codes, the transcripts were coded using NVivo 12 Pro (QSR International Pty Ltd. (2018) NVivo (Version 12)).

Intercoder reliability was assessed while developing the codebook and using combined segment-based Kappa scores calculated by NVivo on two double-coded transcripts (Burla et al., 2008). Coding discrepancies (individual codes receiving Kappa scores of 0.5 or less) were discussed and resolved by the analysis team for all eight interviews, the codebook revised accordingly, and recoding performed when necessary to ensure consistent application of codes. Two members of the research team used the finalized codebook to code the remaining transcripts. Saturation was achieved when no new themes were identified.

3.4 Approach: Quantitative Outcomes

To better understand the dyads being interviewed, quantitative data from an occupationally focused semi-structured interview and a variety of self-reported measures (SRM) were completed by participants. Of the outcomes reported for this study, we investigated SRMs of symptoms and progression in the individuals with PD; and in both members of the dyad, we explored co-morbid health conditions, PD-related quality of life, current levels of physical activity, and stages of change as it relates to engaging in physical activity.

3.4.1 Data Collection & Measures of Occupational Performance

1. ***Canadian Occupational Performance Measure (COPM)***. As noted earlier in section 3.3.1, the secondary interviewer (JSD) administered the Canadian Occupational Performance Measure (COPM) (Law et al., 1990) to each member of the dyad separately on the day of his/her scheduled interview. The COPM immediately followed informed consent and preceded the semi-structured interview framed by the theory of interdependence and communal coping. Although the COPM is also a semi-structured interview, it includes self-reported quantitative measures. Rather than transcribe the COPM as part of the larger interview, we were interested in using the quantitative data to ascertain participants' perceptions of their occupational performance; and relate it to themes and outcomes from the larger semi-structured interviews. Additionally, information gleaned during the COPM, where appropriate, was utilized by the primary interviewer to further prompt participants' responses to the main interview.

As a client-centered outcome, the COPM focuses on occupational performance in self-care, leisure, and productivity. During the COPM, participants are asked to self-identify problematic areas in daily function, namely those things they want to do, need to do, or expected to do. To encourage caregivers to think more holistically about their daily lives, they were prompted with the following sentence, "These can be things that are specific to you individually or personally, or to your caregiving responsibilities." As the COPM progresses, participants are asked to prioritize the occupations, then rate their individual performance and satisfaction on a scale of 1 (lowest) to 10 (highest) in the self-identified occupations. The top three identified occupations were reported. Moderate construct validity (intraclass correlation coefficient [ICC]=.22) and content validity established by a pattern of occupational problems typical for the older adult population (Tuntland et al., 2016) supports utilization of the COPM for older adults with PD.

3.4.2 Data Collection & Self-Reported Measures

Within one week of completing the interview, we mailed SRMs separately to IPDs and their family caregivers, and included an addressed, pre-paid stamped envelope for each member of the dyad to return their forms separately. Nine self-report measures were mailed to participants within one week of completion of their scheduled interview. Five of the nine measures were collected for this study. Of the five applicable to this study, one was specific to the individual with PD, and four were common to both members of the dyad with two measures having variations specific to the IPDs and the caregivers. The additional measures were collected for use in future studies exploring additional factors relative to the interdependence and communal coping theory.

Measure Specific to Individuals with PD

1. ***Parkinson disease progression and symptom presentation.*** To support the qualitative data regarding the dyads' perception of PD progression, we asked participants with PD to assess their disease severity and clinical symptom presentation using two of the four parts comprising the Movement Disorder Society Unified Parkinson Disease Rating Scale (MDS-UPDRS) (Goetz et al., 2008). While subjective, the MDS-UPDRS is the gold standard in clinical assessment of individuals with PD. Part I – Mentation, Behavior, and Mood, evaluated the non-motor experience of daily living; and Part II – Activities of Daily Living considered the motor experience of daily living. Scores range from 0 to 52 for each of the parts, or 0 to 104 for both parts combined, where scores of 52 (for Part I or II separately) and 104 (for both parts) indicate the most severity. Clinimetric analysis of the MDS-UPDRS revealed high levels of internal consistency for the entire scale in addition to high internal consistency for each of the four parts (Part I: α =.79, Part II: α =.90, Part III: α =.93, PartIV: α =.79) (Goetz et al., 2008). Further, the MDS-UPDRS yielded excellent concurrent validity based on total score (r=.96) (Goetz et al., 2008).

Measures Common to Both Members of the Dyad

2. **Demographics and health history**. We collected demographic data and health histories to further explore the impact of co-morbidities in both members of the dyad. Demographic forms were unique to each IPD and CGs to allow for data to be gathered specific to PD. Common to both forms, demographic data of interest for this study included age, gender, ethnicity, smoking history, living situation, education level, employment (work) status, number of health conditions and hospitalizations, self-reported frequency and duration of physical activity per week, and type of physical activity. Specific to the IPD within the health history are questions related to PD, such as age at diagnosis, years since diagnosis, number of years with symptoms prior to diagnosis, side of the body most affected, and presence of PD symptoms (stiffness, bradykinesia, rigidity, tremors, and pain). Both members of the dyad also completed a list of current medications, including length of time taken and dosages.

3. ***Quality of life related to living with Parkinson disease.*** To provide additional comparisons between qualitative outcomes and participants' perceptions about their disease-specific, health-related quality of life, we asked individuals with PD and their family caregivers to complete one of the following Parkinson Disease Questionnaire measures relevant to their position in the dyad:

a. *Parkinson Disease Questionnaire-39* – For individuals with PD, the 39-item PDQ-39 (Peto et al., 1995) examined quality of life through eight scales: mobility, activities of daily living, emotions, stigma, social support, cognition, communication, and bodily discomfort. As a sampling of the questions, participants were to indicate how often in the previous month they experienced various disease-related aspects, such as fear of falling, difficulty with dressing, feelings of isolation and embarrassment, problems with relationships, having distressing dreams, difficulty with speech, and experiencing painful spasms. Participants checked one of five boxes for each question indicating the frequency of the experience: never, occasionally, sometimes, often, or always/cannot do at all. Each scale was scored on a range from 0 (no problems) up to

100 (maximum level of problems). Therefore, lower scores indicated greater quality of life and correlated with decreased disease severity. Conversely, higher scores demonstrated decreased quality of life and correlated with increased disease severity. Researchers found the PDQ-39 to possess good internal consistency (α=.66 to .95 for U.S. version) and reliability (r=.86 to .95 for U.S. version) (Bushnell & Martin, 1999).

b. *Parkinson Disease Questionnaire-Carer.* For caregivers, the 29-item PDQ-Carer (Jenkinson et al., 2012) asked participants to evaluate how caregiving affects their quality of life across four scales: anxiety and depression, self-care, social and personal activities, and stress. As a sampling of questions, caregivers are asked how often during the last four weeks have you not slept enough, felt anxious, thought your caring role was taken for granted, and felt worried. Caregivers checked one of five boxes for each question indicating the frequency of the experience: never, occasionally, sometimes, often, or always. Each scale was scored on a range from 0 (no problems) up to 100 (maximum level of problems). Lower scores indicated greater quality of life and correlated with decreased disease severity. Conversely, higher scores demonstrated decreased quality of life and correlated with increased disease severity. Researchers found the PDQ-Carer to possess good content and construct validity with alpha coefficients ranging from 0.85 to 0.94 for each of the scales (Jenkinson et al., 2012), and good internal reliability with an alpha of 0.94 for the single index (Morley et al., 2013).

4. ***Current levels of physical activity.*** To better understand participants' interview responses regarding occupational participation in exercise as compared to their self-reported levels of physical activity, we asked both members of the dyad to complete the Physical Activity Scale for the Elderly (PASE) (Washburn et al., 1993), a 12-item questionnaire used with older adults, age 65^{+} years. The PASE provides additional details on frequency, duration, and type of physical activity performed during the past seven days, and covers leisure, sport and recreation, muscle strengthening and endurance, as well as house and yard work, volunteer or paid work, and caregiving. Responses to the frequency of an activity category include never, seldom (1-2

days/week), sometimes (3-4 days/week), or often (5-7 days/week). Duration responses include: less than 1 hour, 1-2 hours, 2-4 hours, or more than 4 hours. Household and work activities require a yes or no response; and duration of work activities is requested in hours rounded to the nearest whole number. Total PASE scores range from 0 (completely sedentary) to 400 and above, (with a maximum score of 793 indicating that a participant is extremely active) and are based on the product of time spent in an activity and weights placed on each activity. Weighting of activities was derived from activity trackers, energy expenditure, and self-reporting of physical activity. Washburn et al. (1993) reported mean PASE scores were 125.2 ± 89.9 points; and males tended to score higher than females (145.8 vs. 123.9); adults ages 55-64 years score higher than those over age 65 years (144.2 vs. 118.9). Per Washburn, the PASE has excellent test-retest reliability with the target population of older adults (ICC =0.75) and adequate construct validity with balance (r=0.33), age (r=-0.34), and perceived health status (r=-0.34). Additionally, the PASE has been correlated to resting metabolic rate and energy expenditure which was derived using doubly labeled water; the PASE was found to be an acceptable and valid method (r=.58, CI=0.50-0.81) for categorizing physical activity in older adults (Schuit et al., 1997). Although the PASE scoring method is well established, the scoring system is best applied to large cohorts of individuals. For this study we were interested in the highest level of weekly physical activity that participants engaged in (e.g. walking, strength or endurance activities, light sport or recreation, moderate sport or recreation, or strenuous sport or recreation, where strenuous is the highest level) and the frequency (number of times per week) that they exercised at that highest level. Therefore, summary score data are not presented for each group, rather individual weekly exercise intensity and frequency values are provided.

5. ***Stages of change for physical activity.*** To gain further insights into participants' motivation for participating in exercise, we administered the Physical Activity Stages of Change Questionnaire (PASCQ), adapted from Marcus and Forsyth (2003) based on the Transtheoretical Model of behavior change (Prochaska et al., 1994). The PASCQ asks participants to circle "yes" or "no" in response to four items about their participation in physical activity, namely 1) I am

currently physically active; 2) I intend to become physically active in the next 6 months; 3) I currently engage in regular physical activity (defined in the PASCQ as 30 minutes or more per day for at least 5 days per week); and 4) I have been regularly physically active for the past 6 months. Depending on respondents' combination of answers to the four questions, The PASCQ scoring algorithm assigns one of five stages of change, specifically 1) precontemplation (no intention to change), 2) contemplation (thinking about change), 3) preparation (intending to take action to change), 4) action (modifying behavior), and 5) maintenance (sustained behavior change).

3.4.3 Statistical Analysis of the Quantitative Data

Descriptive statistics were calculated for caregiver and IPD demographics and self-reported measures using Microsoft Excel® (Microsoft Excel® for Windows, Version 16.0.5188.1000, 2016). Values presented are means and standard deviations or raw individual data from each participant, unless otherwise noted.

Results

4.1 Participant Characteristics

Four community-dwelling married dyads with one member of the dyad diagnosed with PD took part in this study. Dyads were comprised of four male IPDs and four female spouse CGs. All participants participated in the semi-structured interviews. Four IPDs and 3 CGs returned the SRMs; as such, participant demographics reflect four IPDs and three CGs. One CG did not fully complete all sections of each form, therefore data are missing from some metrics. See Table 2 for descriptive characteristics of participants.

IPDs were an average age of 77.25 years, and were in presumptive Hoehn & Yahr stage 3, at which there is bilateral involvement of the disease, along with postural instability. All four IPDs were retired white males with some level of post-secondary education. Inclusive of PD, they reported a range of 1-8 chronic conditions, and an average of 1-2 hospitalizations. Regarding participation in physical activity, IPDs reported a mean of 53.75 minutes of exercise per session with a range of 15-90 minutes per session and performed 1.5-5 days per week. IPDs self-reported their level of fitness as poor to above average (Table 2).

CGs were younger than their spouses, at an average age of 72 years. Similar to their spouses, all CGs were white. Two CGs were retired, and one volunteered in a part-time position. They self-reported more chronic conditions and hospitalizations than their IPDs, with a range of 5-8 conditions, and 2-8 hospitalizations. Only two CGs reported on physical activity with one CG indicating 0 minutes per week, the other 15 minutes per session 5 times per week. The three CGs reported their fitness levels as fair to average.

Table 2. Participant demographic information.

Demographic Variable	**Participant**	
	IPD (n=4)	CG (n=3)
Age (mean yrs)	77.25	72
Gender (n)	male (4)	female (3)
Race (n)	white (4)	white (3)
Marital Status (n)	married (4)	married (3)
Highest Level of Education, (n)	Post college education (1), Bachelor's degree (2), Associates degree (1)	Bachelor's degree (1), High School Diploma (1), NR (1)
Current Employment, (n)	Retired (4)	Retired (2), NR (1)
Annual Household Income, (n)	$80,000 or greater (1), $70,000-79,999 (1), $50,000-59,999 (1), $30-39,999 (1)	$80,000 or greater (1), $70,000-$79,999 (1), $30-$39,999 (1)
***Presumptive Hoehn & Yahr Stage of PD**	3 (4)	
Side Most Affected by PD, (n)	Right (2)	
Number of Chronic Conditions (including PD)	1, 3, 5, 8	5, 7, 8
Average Number of Hospitalizations	1, 2, 2	2, 5, 8
Duration of Exercise per Session (minutes, range)	mean = 53.75 mins (min = 15 mins, max = 90 mins)	0 mins, 15 mins, NR
Number of Times Exercising per Week	1.5, 2, 3, 5	0, 5
Self-Rated Fitness Level	Above average (1), Average (2), Poor (1)	Average (2), Fair (1)

* Individuals were not able to be examined in person to determine H&Y score; NR = no response recorded

4.2 Results of the Semi-Structured Interviews

Semi-structured interviews were conducted with four IPDs and four CGs using questions based on the interdependence model with communal coping. Three major themes were identified that addressed the perception of PD as a threat to the health and well-being of PD care dyads and influenced their occupational participation in physical activity: 1) Progression of Parkinson Disease, 2) Perception of PD as a Threat, and 3) Factors Influencing Participation in Exercise. For individuals with PD, the "disease throws a curveball every day"; while for caregivers, PD means they are "trying to keep all the balls in the air." For the dyad, the threats imposed by the disease "keep them watching from behind" for each other's health and well-being. Taken together, the perceived threat of PD influences the dyads to participate in exercise, because "staying strong = staying healthy."

A complete list of codes is presented in the saturation grids (Tables 3, 5, and 7), along with exemplary quotes (Tables 4, 6, and 8), which typically represent codes referenced more than 40 times and with a minimum saturation of 6 out of 8 individuals. Saturation was reached when no new themes were identified. The corresponding saturation grids and quotes are presented following the descriptive narrative for each theme and supporting subthemes, with a description of the relevance to the experiences of IPDs and CGs.

4.2.1 Theme 1: Progression of PD – "Throwing Curveballs" & "Keeping Balls in the Air"

For IPDs, the progression of the disease and the efforts to control the unpredictable nature of the symptoms continually present challenges, or in the words of one participant: *"I find that Parkinson's throws a new curveball at me just about every day. When I think I'm doing well with something, something else goes wrong. I follow [sic] that all of the sudden there's just so many issues that Parkinson's brings to the table. Then I get uh, more than a little depressed at being able to handle it all."*

Their CGs are reciprocally affected by the challenges as they take on more activities related to providing care, over and above their usual and customary daily occupations. In referring to her increasing responsibilities, one caregiver repeated multiple times throughout her interview: *"You just can't keep all those balls in the air."* She went on to explain: *"[I] try to kind of keep tabs on where we are? Who are we seeing? Who are we supposed to be seeing? I mean, I still have a couple of hookups that I still haven't made. I still haven't gotten into a physical therapist, and I think there's one other, but I can't think of who it is. But because you do this, you can't see everybody at once. You can't keep all those balls in the air."*

Although both members of each dyad were interviewed separately and on different days, the communal effects of these two themes were often reflected by the dyads and across the subthemes of managing ADLs and daily routines, managing medical needs, the IPDs' increasing reliance on their caregivers, and the resultant effects on the caregiver's self-needs.

Managing ADLs and Daily Routines

When discussing their daily occupations, caregivers often noted all the tasks they were undertaking during the day, and the limited help their IPD spouses were able to offer, whether that was due to physical limitations or problems with motivation.

> **CG:** *He can be reading all day long…sometimes, he is doing more reading because he can't physically do a lot of the things that he used to do. … So this is kind of taking the place of that, which I'm glad he does have something that he enjoys doing. But sometimes it seems like I'm working and cleaning and doing laundry. He does help me fold the laundry, that he does. If I'm unloading the dishwasher, he comes in and he helps me put the dishes away, but it's just that he can't go out, do things that he normally would in the garage or pick something and do something on his own.*

In contrast, the IPDs would discuss the activities and chores they still tried to help with around the household:

> **IPD:** *We do the chores around the house. Although she doesn't let me do a whole lot around the house. It's alright if I go out and rake the lawn, though. But, I try and vacuum the house, but she doesn't let me sometimes. (sniffles)…The lawn's gonna need mowin'. It's going to need mowin'. You're going to have to do it. Or hire somebody to get it done.*

Managing Medical Needs

In addition to daily occupations and ADLs related to household management and controlling the symptoms of PD, the dyads spent a considerable amount of time discussing their medical needs and interactions. One IPD mentioned that doctor visits comprised a majority of the time they spent doing things together:

> **IPD:** *But that's a big part of our lives, going from one doctor to another. I mean, our calendars filled up with doctor appointments.*

Caregivers were heavily involved in managing all the medical needs for their spouses, as well as themselves. Their involvement included the administrative aspects of making appointments, accompanying their IPDs to the appointments, and then advocating on behalf of their spouses, often to ensure that they received treatment relevant to their symptom presentation.

> **CG:** *I try to go along to all the doctor appointments. There were times in the last couple of years I just couldn't. When I was immobile with the broken leg. But I do try and go along so that there is a second person hearing it, but in this case, I understand medical terminology and I can use medical terminology and that sometimes helps when I do that, because he'll just say it hurts and I will throw in the medical terminology "it hurts in these parts with the correct term", which helps them focus. He's like, well, "the doctor should be able to figure that out if I just point to it and say it hurts".*

> **IPD:** *When it comes to going to the neurologist for adjustments in the DBS, um, she goes along with me, I just, because it's you know, it's sometimes better to have two, two people listening. Sometimes she hears things differently than I do. And when that happens, she's usually the right one, you know.*

IPDs’ Increasing Reliance on their Caregivers

With the progression of the disease, IPDs have had to admit their increasing reliance on their spouses, but at the same time were adamant about the activities they are still able to do independently.

> **IPD:** *I like to regard myself as an individual that can stand by myself. I don’t need help. But I do now, and she helps me in those areas that, uh, I either I’m very uncomfortable or it takes me a long time to do…to doing it totally and being not being able to do it and she does it for me.*

> **IPD:** *It's important to do this stuff that I can still do. I can still shovel snow and hold on to it and do a lot of other physical activities, while not being able to lift as much or do it quickly, I am still able to do it, and I try to do those that I can.*

Echoing their IPDs, caregivers noted their spouses were becoming more dependent on them, oftentimes requiring the CG to step in either to do things the IPD was previously capable of doing or should be doing independently. CGs also noted they regularly had to step in as a way to react to or control a situation.

> **CG:** *First of all, he wasn't driving at that time. He needed me to drive him, but secondly, I wasn't sure that he would be able to express himself because he can't. His speech fails to sometimes route and so I sort out the medications and try to ask about things that are kind of rolling along.*

> **CG:** *At first, when he was starting his tube feedings, I felt compelled to be there. But I’ve told him, you know, he can handle it and he does really fine with it…If it’s inconvenient for him to have to get up and down to pour water, and that kind of thing. So, you know, if I’m going to get up anyway, I might as well get up and give him a hand with that.*

> **CG:** *Maybe I'm, maybe I'm taking some of the things that he should be doing on his own. Like his pills that he has to take a half an hour before he eats. Every night he watches Jeopardy at 4:30, it's very easy to remember, but he should be taking his pill at 4:30 because we eat at 5:00. But I could be in the kitchen making dinner and Jeopardy is on and the pills are still sitting on the counter. So, I have to go in there and say, "It's pill time." And if I don't, if I don't remember it, I don't know if he would.*

> **CG:** *Look you can't take a soda can out and try and pour yourself a soda in the morning, because how many times have you spilled that all over the counter and all over the floor when I have to clean that up in the morning? Then I have a problem. He doesn't like to not be able to do those things, but the reality is he has a grip problem. Yes, it's another one he doesn't admit to.*

Minimizing the Self Needs of the Caregiver

For caregivers, the consequences of "keeping all the balls in the air" due to their spouses' progression of PD typically meant they had to sacrifice and minimize their own physical well-being, self-care, and personal needs, as illustrated by the following examples.

> **CG:** *In the morning with the spaghetti, somebody has to do that. It can't lay on the floor, or the dog, you know, shouldn't be ingesting strings of spaghetti. He can't do it. I've got to. And I'm paying for it, right? You know, today it was with my knee; because my knee wasn't ready to fold like that, you know, at 8:00 in the morning.*

> **CG:** *Well, when he was so ill, I was sleeping very lightly. And so I moved, because I was sleeping so lightly, I was afraid of bothering him. So I moved to the other bedroom in our condo.*

> **CG:** *I guess there's really not time to myself, because we're together, we do everything together. But I do like to read or crochet and so I do find that if I can move into a different room. And do some of these things on my own that I enjoy. (Laughs) [It's] hard to figure out, [but] (sighs) maybe an hour a day. I can take an hour a day, maybe.*

For three out of the four dyads interviewed, the caregivers were the only ones to mention how they minimized their own self-needs. However, in the fourth dyad, the concept of minimizing took on a negative connotation between the partners, such that they minimized each other. No other dyad did this:

> **PD:** *She doesn't really pay that much attention to how I do [the checking account] or to how I take money out of my other account. And but she'll say, you know, that she does all this stuff for me around here. But when I'm gone, there won't be anybody to take her role, to take care of her. And so, she's really going down the road just by herself. And she is. So, there's not much I can do about that.*

> **CG:** *He's just a real stick in the mud. I mean, it's just kind of his nature. But now, like, way more. And so, I constantly like, he just found out he can't drive at night. I really should be taking a license away. I know. But I feel like I almost feel like I'm giving him the best gift I could ever give him by allowing him to still drive, knowing that I'm probably going to die in the car.*

Although the fourth dyad was unique in relation to the other three, which will be addressed further in the discussion, the progression of the disease had profound impacts on the daily occupations of all IPDs and their spouse CGs. Of particular note were the similarities in comments and stories between the partners of each dyad as they discussed the unpredictability and progression of the disease

Table 3 – Theme 1: Saturation grid of the themes for progression of PD.

Themes & Subthemes	# of References	CG 01	IPD 01	CG 02	IPD 02	CG 03	IPD 03	CG 04	IPD 04
Progression of PD *IPDs – “PD Throws a Curveball Everyday* *CGs – “Keeping All the Balls in the Air”*									
• Controlling PD and the Sx	106*	X	X	X	X	X	X	--	X
• Relying on or depending upon the caregiver	52*	X	X	X	X	--	X	--	X
○ Insisting on independence (PD) & still doing things	33*	--	X	X	X	X	X	X	X
• Managing and being a decision maker									
○ Managing ADLs & the routine of PD	98*	X	X	X	X	X	X	X	X
○ Handling things	52*	X	X	X	X	X	X	--	X
○ Stepping in	47*	X	X	X	X	X	--	X	X
○ Role in the household	26	X	X	X	X	X	X	--	X
○ Trusting the person’s capabilities	18	X	--	X	--	X	--	--	--
• Managing medical									
○ Interacting with & identifying needs	173*	X	X	X	X	X	X	X	X
○ Administrative & logistical	60*	X	X	X	X	X	X	--	--
○ Advocating & accompanying	42*	X	X	X	X	X	X	X	X
○ Influence & involvement of family	36	X	X	--	--	X	--	X	X
• Minimizing the caregiver									
○ Sacrificing, downplaying or neglecting	50*	X	--	X	--	X	--	--	X
○ Self-needs and time to self (CG)	26*	X	X	X	X	X	--	X	--
○ Minimizing sense of self	22	X	X	X	X	--	--	X	X
○ Problems with sleep	15	X	X	X	--	X	X	X	--
• Dealing with transitions	22	X	--	X	X	X	X	--	--
○ Problem solving	7	X	--	X	--	X	--	--	--
○ Not being ready	11	X	--	X	--	--	X	--	--

Key: * indicates themes for which quotes are provided in Table 4

Table 4 – Theme 1: Quotes reflecting the progression of PD.		
Themes & Subthemes	**Caregiver Quotes**	**Individual with PD Quotes**
Progression of PD	***"Keeping All the Balls in the Air"***	***"PD Throwing a Curveball Every Day"***
Controlling PD and the symptoms	His speech fails to sometimes route and so I sort out the medications and try to ask about things that are kind of rolling along. And just to kind of keep tabs on where we are? Who are we seeing? Who are we supposed to be seeing? I mean, I still have a couple of hookups that I still haven't made. I still haven't gotten into a physical therapist, and I think there's one other but I can't think of who it is. But because you do this, you can't see everybody at once. You can't keep all those balls in the air.*	So I find that with Parkinson's throwing a new curveball at me just about every day. When I think I'm doing well with something, something else goes wrong. I follow that all of the sudden there's just so many issues that Parkinson's brings to the table. Then I get uh, more than a little depressed at being able to handle it all.*
Relying on or depending upon the caregiver	First of all, he wasn't driving at that time. He needed me to drive him, but secondly, I wasn't sure that he would be able to express himself because he can't. His speech fails to sometimes route and so I sort out the medications and try to ask about things that are kind of rolling along.*	I like to regard myself as an individual that can stand by myself. I don't need help, but I do now and she helps me in those areas that uh I either I'm very uncomfortable or it takes me a long time to do...to doing it totally and being not being able to do it and she does it for me.* So I thought I was fairly, fairly well at taking care of her, but not nearly as, as much time spent doing that as she spends taking care of me now. She doesn't need me. And I need her.+
Insisting on independence and still doing or holding onto things (IPD)	Look you can't take a soda can out and try and pour yourself a soda in the morning, because how many times have you spilled that all over the counter and all over the floor when I have to clean that up in the morning? Then I have a problem. He doesn't like to not be able to do those things, but the reality is he has a grip problem. Yes, it's another one he doesn't admit to.	It's important to do this stuff that I can still do. I can still shovel snow and hold on to it and do a lot of other physical activities, while not being able to lift as much or do it quickly, I am still able to do it, and I try to do those that I can.
Managing ADLs and daily routines	He can be reading all day long…sometimes he is doing more reading because he can't physically do a lot of the things that he used to do. … So this is kind of taking the place of that, which I'm glad he does have something that he enjoys doing. But sometimes it seems like I'm working and cleaning and doing laundry. He does, help me fold the laundry that he does. If I'm unloading the dishwasher he comes in and he helps me put the dishes away, but it's just that he can't go out, do things that he'd normally would in the garage or pick something and do something on his own.*	We do the chores around the house. Although she doesn't let me do a whole lot, around the house. It's alright if I go out and rake the lawn, though. But, I try and vacuum the house but, she doesn't let me sometimes. (sniffles)…The lawn's gonna need mowin'. It's going to need mowin'. You're going to have to do it. Or hire somebody to get it done.*
Managing the routine of PD	So, yeah, so we just get up in the morning and I don't feel compelled to get up as soon as I hear him anymore. At first, when he, he was starting his tube feedings, I felt compelled to be there. But he's, I've told him, you know, he	I usually wake up about 6:00 o'clock. I have to take my carbidopa levodopa medication. And I also have to take a, uh my nutrition drink. Through my gastro tube so I have to take my carbidopa levadopa medication either an hour

	can handle it and he does really fine with it. It's, it's inconvenient for him to have to get up and down to pour water, and that kind of thing. So, you know, if I'm going to get up anyway, I might as well get up and give him a hand with that. Um, so he does his tube feeding.*	before or an hour after I take the nutrition drink, otherwise they're fighting themselves for absorption. So my first activity of the day is. Getting set up, taking medication, and getting set up for my first feeding in the morning through the gastric tube.*
Handling things	[When he was in the hospital] it wasn't a very good experience. They had changed his room into a double room, and it was just like a nightmare…My focus was on getting him out of there…And so once I knew what the problem was and I could get him home and take care of it, that's I just would. We're outta here just calling my son now; we're going to leave you now.	Well, I think back to when she had her surgery. That was four years ago and five, so... (pauses) I wasn't as progressed in my disease, … I cooked the meals…did the shopping, the washing, folded the clothes, put 'em away, cleaned the house, um... (pauses). Made sure she had her medicine, although she took care of getting them in the proper time. But I would give the medicines to her. So I thought I was fairly, fairly well at taking care of her, but not nearly as, as much time spent doing that as she spends taking care of me now.+
Stepping in	Maybe I'm, maybe I'm taking some of the things that he should be doing on his own. Like his pills that he has to take a half an hour before he eats. Every night he watches Jeopardy at 4:30, it's very easy to remember, but he should be taking his pill at 4:30 because we eat at 5:00, but I could be in the kitchen making dinner and Jeopardy is on and the pills are still sitting on the counter. So I have to go in there and say "it's pill time". And if I don't, if I don't remember it, I don't know if he would. **CG:** "At first, when he was starting his tube feedings, I felt compelled to be there. But I've told him, you know, he can handle it and he does really fine with it…If it's inconvenient for him to have to get up and down to pour water, and that kind of thing. So, you know, if I'm going to get up anyway, I might as well get up and give him a hand with that.*	Yeah, shoes, um, just generally helping me with stuff that uh is a little harder for me to do. It's not that I can't do it, but she helps me with it. Usually sometimes I ask her, sometimes I don't. Then she just comes in and helps me.*
Managing medical: Administrative & logistical	I do a lot of the figuring out the medications. How much does he have on hand? How much do we need to have on hand? When we decide for like our Part D Medicare, every year, I go through all the plans to see which one has what kind of pharmacy services. And for the drugs that we take, we both, each one of us, takes one medication that's quite expensive. And so I try to figure out for a year, what our meds should cost…And I actually have a spreadsheet that I made and I put everything on. So getting the Part D settled at this time of year is always a big deal.	But that's a big part of our lives, going from one doctor to another. I mean, our calendars filled up with doctor appointments and we've got good insurance and it's not a financial issue cause the insurance companies and Medicare pay for just about everything.
Managing medical: Advocating & accompanying	I try to go along to all the doctor appointments. There were times in the last couple of years I just couldn't. When I was immobile with the broken leg. But I do try and go along so that there is a second person	Well, doctors' appointments, I usually make those myself, but when it comes to going to the neurologist for adjustments in the DBS, um, she goes along with me, I just because it's you know, it's sometimes better to have two,

	hearing it, but in this case, I understand medical terminology and I can use medical terminology and that sometimes helps when I do that, because he'll just say it hurts and I will throw in the medical terminology "it hurts in these parts with the with the correct term", which helps them focus. He's like, well, "the doctor should be able to figure that out if I just point to it and say it hurts".*	two people listening. Sometimes she hears things differently than I do. And when that happens, she's usually the right one, you know.*
Managing medical: Interacting with & identifying needs within the medical community	I felt like that there were changes in his Parkinson's and he needed someone who focused on Parkinson's disease. He needed a movement disorder, position neurologist. So I kind of wanted him to go back to Dr. [name] and mentioned it a couple of times. And then finally at his, at an appointment—I don't know, maybe a few months ago—I mentioned something about should he possibly see or get a second opinion on what was happening with his medications?*	Very early on when I was diagnosed, I went to my general practitioner. Sort of jokingly said, well, how long is it before I end up in a wheelchair hunched over and drooling. That took him by surprise, and he said, "Well, that's up to you I guess."*
Minimizing the caregiver: Sacrificing, downplaying or neglecting self	In the morning with the spaghetti, somebody has to do that it can't lay on the floor or the dog, you know, shouldn't be ingesting strings of spaghetti. IPD can't do it. I've got to. And I'm paying for it, right? You know, today it was with my knee because my knee wasn't ready to fold like that, you know, at 8:00 in the morning. Well, when IPD was so ill, I was sleeping very lightly. And so I moved, because I was sleeping so lightly, I was afraid of bothering him. So I moved to the other bedroom in our condo.	The following quotes are to exemplify how CG#004 and IPD#004 minimize each other. No other dyad did this: She doesn't really pay that much attention to how I do [the checking account] or to how I take money out of my other account. And but she'll say, you know, that she does all this stuff for me around here. But when I'm gone, there won't be anybody to take her role, to take care of her. And so she's really, going down the road just by herself. And she is; so, there's not much I can do about that. He's just a real stick in the mud. I mean, it's just kind of his nature. But now, like, way more. And so I constantly like even like he just found out he can't drive at night. I really should be taking a license away. I know. But I feel like I almost feel like I'm giving him the best gift. I could ever give him by allowing him to still drive, knowing that I'm probably going to die in the car.
Self-needs and independence (CG)	After dinner is the usual type of cleanup. I do sometimes 5:30 to 6:30 is news and jeopardy. That's kind of a sacrosanct period for me. I probably will do some work. That's when I will do my kind of bike riding. I guess there's really not time to myself, because we're together, we do everything together. But I do like to read or crochet and so I do find that if I can move into a different room. And do some of these things on my own that I enjoy. (Laughs)[It's] hard to figure out [but] (sighs) maybe an hour a day. I can take an hour a day maybe.*	Again, I sort of take over and I want, when I do it [PD-specific therapy] is when I wanna do it. Not when somebody tells me to do it. I still drive and she doesn't like to drive, so that's one thing that I can do that, you know, she can drive, but I know she'd rather I drove.*

Key: * indicates quotes from the same dyad; + indicates quotes repeated elsewhere to denote overlapping concepts

4.2.2 Theme 2: Perception of PD as a Threat – "Watching from Behind"

Along with the increasing impact on daily occupations, the perceived threat of PD elicited by the ever-advancing symptoms and poor health conditions of both members of the dyad evoked comparisons to past capabilities, and accounts of loss, as well as intensified feelings of burden, frustration, sadness, and worry. For three out of the four dyads, the perception of PD as a threat led them to look out for each other in the face of this loss and uncertainty. As one caregiver described it: "*I've kind of gotten used to watching him from behind."* In a similar fashion, an IPD noted: *"You know, we try and work together so that we're both safe."* For the majority of the subthemes reflecting the major theme, "Perception of PD as a Threat," the communal effects were again evident within dyads. Below are excerpts that illustrate the supporting subthemes.

Acknowledging PD Symptoms & Identifying CG Health Problems

With the progression of PD, the threat of the disease magnifies, such that both CGs and IPDs had to acknowledge the development of additional symptoms, and the impact those changes had on each other.

> **CG:** *Um…I think just his mental acuity. He's a very smart man, and um, it really, I think his biggest worry is that he won't be able to verbalize. And he's probably lost 20% of his vocabulary as it is. And that really bothers him a lot.*
>
> **IPD:** *Um..yeah this is another thing about Parkinson's that I don't like is that you think about it, you know what you want to say, but you can't find the right words to express it. I don't know that CG has…I feel that it's not fair for her to have to deal with my symptoms.*

Co-occurring with the development of new symptoms in IPDs, all participating CGs were experiencing their own health problems, often requiring daily management of their symptoms, in addition to those of their IPDs.

> **CG:** *Well, I always feel that he is worried if I do too much because I did have open heart surgery… With my diabetes, we always have to keep watching it. You know, if my blood sugars get too low and like I say, I do have this beeper that will go off and beep if I get too low which is really a help. Before that, you have to rely on how you felt and then you have to poke your finger to see it.*

> **IPD:** *She's had enough on her plate right now to deal with her, her problems for some of her health twice her physical health issues and some mental issues like trying to help me. She was overweight for quite a while, and then when I was diagnosed with Parkinson's, she gained a lot of weight… She's got other issues too. She had a knee replaced a while ago... (pause). Her vision is not as good as it used to be. Her iris got messed up with, um, with some treatments that they're giving her… And she's got a problem with her, um, pancreas, which is really a huge problem that could be life threatening for her.*

With the acknowledgement of advancing PD symptoms and the waning health of caregivers, the dyads often expressed concerns that decrements in the CGs' health would ultimately affect their ability to care for the IPDs.

> **CG:** *It's important to me that he will probably say sometimes that I, and I would admit I do this, I will put him ahead of me. So, I've got to learn to be a little bit more vocal about the time that you know, the things that I that I need. Physical, I have to, I mean.*

> **IPD:** *And her concern is, you know, that if something happens that I get injured or she gets injured, how are we going to deal with that as a couple and, you know, and I'll acknowledge that it will be a problem…I'm concerned that if something happens to her,*

> *if she has a fall, that I won't be able to pick up her slack because we've been through that once (crying)...*

Contrasting and Comparing the Past

For both members of each dyad, the perception of the threat was also evident in their recollections of how the IPD used to be, and what he was capable of before the PD diagnosis.

> **CG:** *He doesn't see it, but I do know and I'm seeing this falling off and it's just really, really hard. You know, when he was working as a [professional]. He would have two or three screens going at the same time, complicated documents, flipping back and forth on the phone with somebody, you know. And this is the guy now that I have to drive the train to help him understand what would have been so simple for him five years ago. Just, you know, it's just hard for me to watch this happen. But, you know, it is what it is.*

> **IPD:** *Well, you know, it used to be that when I was working and before I had PD, I could get up and get dressed and be out the door in half an hour, you know, now it takes me longer but I used to do the same things. You know, so and I'm still doing the same thing, but not at the same speed.*

Experiencing Loss

The act of comparing and contrasting the past to the present was closely linked to accounts of losing something cared about. Though all dyads talked about these losses, it is of note that there was little overlap within a dyad about the focal point of the loss, such that the caregiver and the IPD usually mentioned different losses. Where CGs would typically focus on the loss of things the couple did together, the IPDs focused on things they did independently.

> **CG:** *We used to go fishing all the time. You live on a lovely lake and that's normally what you want to do. And he just doesn't seem like he has the desire to do it anymore. But one night I was so bored. It was like nothing, nothing. For how long? And I actually got up several times and sat on the deck. It was a beautiful night. "We should be out fishing (laughs) not sitting here watching the ballgame. Not that I don't enjoy our times, but I just think that we're missing so much.*
>
> **IPD:** *I was a band director. I used to play in the community bands and about four years ago I dropped out, because of my physical limitations. I don't have enough breath control to play the musical phrases the way they're supposed to be. I have to breathe more frequently than the music would allow me to. And that was, uh, the section that I was in, there were four of us in the first section. And all four of us were high school band directors, so it was very competitive and um, I just couldn't compete anymore. And I didn't wanna, I didn't watch some kind of a charity thing where they just put me somewhere in the band.*

In the latter example, the IPD notes multiple losses, but the one that was consistently mentioned within and across dyads was the loss of strength or stamina, and the idea of regressing.

> **CG:** *Well, he's already admitted that he thinks that things are getting worse, especially when he doesn't feel really good at different times, and the fact is that he doesn't have the stamina to do anything. So, we went for a walk one night and he just took his cane, and we stopped several times, and he leans on his cane…We only got just right around the corner a little ways, like we normally would have walked a lot further. But it seemed like it was a chore for him.*
>
> **IPD:** *I resigned myself to the fact that I'm never going to regain the strength that I had, I'm never going to regain the stamina I've had. I look back over the last five years and*

> *I've had blood pressure problems, uh, stamina problems... All kinds of physical problems. And I just don't see coming back to anything near what I was.*

Intensified Feelings and Worry about an Uncertain Future

Throughout the interviews, both members of the dyads regularly conveyed their feelings of burden, frustration, anger, sadness, and worry about the impending future. These constructs of emotion often co-varied within small blocks of dialogue. Beginning with feelings of burden and onus, both the IPDs and the CGs acknowledged the burden of caregiving.

> **IPD:** *I feel that it's not fair for her to have to deal with my, with my symptoms. With, with things the way they are, but she does and..well, I say she didn't bargain for that. So, there's a big question mark there as far as what the future holds for me and sometimes worries me, 'cause I don't want the care portion of it dumped on CG.*

> ***CG:*** *That's tremendous pressure…It's big, it's...because I'm the medical person in my family, I always get to make these decisions [begins crying].. I don't wanna make this decision anymore… So this is my biggest long-term problem. I don't have to face it today, but it's out there… I have cried a lot of tears over it, but it's not something that you can really even share easily with your family with your children. I mean, it's mine.*

> **IPD:** *She seems to be holding up pretty well as far as what she feels her role as caregiver is. I'm feeling funny about it, 'cause I feel it getting more and more of a burden. But we do have long term care insurance and financially I'm not so worried as I am about the timing of the whole thing.*

> **CG:** *I think the short term is keeping him on track and trying to help him get stronger. The longer term is our life situation…and wondering, you know, where is it going to end*

> *and how is it going to end? Yeah, because I don't know and we might not know…There is no crystal ball.*

Feelings of anger, annoyance, and frustration were also expressed by all eight interviewees, predominantly directed at their partners.

> **CG:** *I've almost got to rehearse the conversation. So, I try and give it because otherwise he gets real frustrated with me if he isn't understanding anymore…and then he gets frustrated with me because he yells at me and he says, "Yes, well you gotta explain it in the way that I can understand it". And I'm like, "You know, and you've done it three times that you haven't gotten it right yet". It's like, I'm trying, but I just don't know what the verbiage is that he's going to understand what to me is a crystal clear sentence.*

> **IPD:** *Well, I think [she] comes to the table trying to make things better for me. But in doing that, I think she may feel that she's getting a little too bossy about the whole stuff and she gets some vibes from me that she shouldn't be sticking her nose in my business and that kind of stuff, so very often times, now I can't say very often, but sometimes I get a little irritated and that makes her work just that much more difficult. A lot of times my anger is not at her but it's at the disease. But I know I've got nowhere else to uh, to uh place it.*

Watching from Behind because PD Makes it Harder

Tied closely to the emotional impacts of the disease, especially worry, the theme of "watching from behind" suggested that both members of the dyad, but CGs in particular, felt compelled to be vigilant and to watch out for their IPDs' safety.

> **CG:** *On his second trip in [to the house], I noticed that he knocked into the door jam, and then he knocked into the other one. It was like then I just dropped what I had, and*

> *grabbed him, because he was weaving. So, I guess I've kind of gotten used to* ***watching him from behind.***

> **IPD:** *Everything she has to do is, she certainly can't do it anymore. That's a concern. Well, I don't know what else to do. You know, we try and work together so that we're both safe.*

The idea of "watching from behind", as a way to look out for each other was regularly communicated in 3 out of the 4 dyads, who also commonly noted doing things together and expressed a sense of belonging and commitment to one another.

> **CG:** *I promised him that I would be his partner in this years ago, and I think that I have. I think I've been an equal partner.* …I'm ready to commit to this for another seven years, if that's what it takes. I'll be here for the whole ride…*I just love this man so much. He's been my heart and soul for 50 years.*

> **IPD:** *CG and I have gone through more than 50 years of marriage and three kids very well, I think. We work together as a team and we put it together and for the most part, it, it was a lot of fun looking back at it..and it still is. But the Parkinson's makes it a lot harder.*

> **CG:** *Yeah, at least we've made such a great team and it's just it's hard for me because that's the hardest thing for me right now is the guy I used to know has really changed. He doesn't see it, but I do know and I'm seeing this this falling off and it's just really, really hard.*

In contrast to the first three dyads, neither member of the fourth dyad discussed the idea of watching out for each other's safety. Although they talked about doing things together, their comments were discordant, and neither brought up the theme of belonging in the context of their relationship.

> **IPD:** *I guess I'm not, um... (pause). I'm not going, I will not come up with a lot of things that we do together other than just the routine things like went to, going to a show, going to out to eat once in a while and those kind of things, and um, I don't think at this point they haven't interfered with our, our uh, working or being together. (IPD#004)*
>
> **CG:** *You know, finding things that we could do together I think would be so good for us. We walk, it's along a country road, so we have to walk single file and drag the dog along. It's meant to be, I don't know, side by side. But, you know, I just think the camaraderie thing is something we have never really been able to build.*

As with the previous theme, the remarks made by the fourth dyad, particularly as it related to doing things together and their sense of belonging suggested that their individual perceptions of the threat of PD differed. Whereas, the other three dyads again demonstrated communal responses that often reflected their partners’ comments about the perceived threat of PD to the health and well-being of both members of the dyad.

Table 5 – Theme 2: Saturation grid of themes for perception of PD as a threat.

Themes & Subthemes	# of Refs	CG 01	IPD 01	CG 02	IPD 02	CG 03	IPD 03	CG 04	IPD 04
Perception of PD as a Threat *Dyad – "Watching from Behind"*									
• Admitting and accepting	148*	X	X	X	X	X	X	--	X
• Acknowledging PD Sx	124*	X	X	X	X	X	X	X	X
• Identifying caregiver's health	108*	X	X	X	X	X	X	X	X
○ Prioritizing caregiver's health	24	X	X	X	X	X	X	--	--
• Contrasting, comparing the past	91*	X	X	X	X	X	X	X	X
• Experiencing loss/losing something cared about	42*	X	X	X	X	X	X	X	X
○ Losing strength/ground	46*	X	X	X	X	X	X	--	--
○ Losing or gaining self-esteem	9	X	X	--	--	--	--	--	--
• Intensified emotions									
○ Worry	99*	X	X	X	X	X	X	--	X
○ Burden or onus	66*	X	X	X	X	X	X	--	X
○ Angry, annoyed, irritated	63*	X	X	X	X	X	X	X	X
○ Sadness or depression	49*	X	X	X	X	X	X	--	X
• Watching from behind (looking out for each other)	56*	X	X	X	X	X	X	--	--
• Uncertainty of the future	76*	X	X	X	X	X	X	--	X
○ Planning for the future	36	X	X	X	X	--	X	--	X
• Doing things together	46*	X	X	X	X	X	X	X	X
○ Belonging (marriage)	17	X	X	X	X	X	X	--	--
• Denying or shifting blame	34	X	X	X	X	X	X	X	X
• Other emotions									
○ Hope, joy, gratitude	38	X	X	X	X	X	X	X	X
○ Confidence & self-efficacy	24	X	X	X	X	--	X	X	--
○ Frustration	23	--	X	X	--	X	X	X	X
○ Different or embarrassed	18	X	--	--	X	X	X	--	X
○ Lifting burden or freeing	16	X	--	X	--	--	--	--	
○ A sense of urgency	13	X	--	X	--	X	--	--	X
○ Compelled	9	X	X	X	X	--	--	--	--
• Coping Mechanisms									
○ Using exercise	9	X	X	X	X	--	--	--	--
○ Managing emotions	12	X	X	X	X	--	--	--	X
○ Other mechanisms	12	X	--	X	--	X	--	X	--
○ Role of family	6	X	--	--	--	--	--	X/-	X/-
○ Spirituality	24	X	--	X	X	--	--	--	--

Key: * indicates themes for which quotes are provided in Table 6; - indicates a negative effect of the subtheme

Table 6 – Theme 2: Quotes reflecting the perception of PD as a threat.

Themes & Subthemes	Caregiver Quotes	Individual with PD Quotes
Perception of PD as a Threat	*"Watching from behind in the face of uncertainty and loss"*	
Admitting and accepting	We were in the doctor's office and IPD said, "Well, I guess there is one more issue and that's I'm depressed." And I almost fell off the chair that he admitted it. It was huge…And so we got home, and I said, "I'm glad that you were finally able to identify this," and I tried to get, you know, some things out. And then I said, " I knew that it was going on 'cause you don't talk to me when you're depressed, and you hadn't been talking to me, so you haven't talked to me for about a month. So I know that things are not going well for you."*	You'll say, but what good is this gonna do? I'll do this in another hour. I'm tired right now I'm gonna go take a nap. Just finding ways to, uh, get around it. That's part of the depression medication. That's sort of the attitude that I started taking the depression medication.*
Identifying or acknowledging PD Sx	Um…I think just his mental acuity. He's a very smart man, and um, it really, I think his biggest worry is that he won't be able to verbalize. And he's probably lost 20% of his vocabulary as it is. And that really bothers him a lot.*	Um..yeah this is another thing about Parkinson's that I don't like is that you think about it, you know what you want to say, but you can't find the right words to express it. I don't know that CG has.. I feel that it's not fair for her to have to deal with my symptoms.*
Identifying the caregiver's health conditions	Well, I always feel that he is worried if I do too much because I did have open heart surgery… With my diabetes, we always have to keep watching it. You know, if my blood sugars get too low and like I say, I do have this beeper that will go off and beep if I get too low which is really a help. Before that, you have to rely on how you felt and then you have to poke your finger to see it.	She's had enough on her plate right now to deal with her, her problems for some of her health twice her physical health issues and some mental issues like trying to help me. She was overweight for quite a while, and then when I was diagnosed with Parkinson's, she gained a lot of weight… She's got other issues too. She had a knee replaced a while ago... (pause). Her vision is not as good as it used to be. Her iris got messed up with um, with some treatments that they're giving her… And she's got a problem with her um pancreas, which is really a huge problem that could be life threatening for her.
Prioritizing caregiver's health	It's important to me that he will probably say sometimes that I, and I would admit I do this, I will put him ahead of me. So I've got to learn to be a little bit more vocal about the time that you know, the things that I that I need. Physical, I have to I mean.*	And her concern is, you know, that if something happens that I get injured or she gets injured, how are we going to deal with that as a couple and, you know, and I'll acknowledge that it will be a problem…I'm concerned that if something happens to her, if she has a fall, that I won't be able to pick up her slack because we've been through that once (crying).*
Contrasting, comparing the past	He doesn't see it, but I do know and I'm seeing this falling off and it's just really, really hard. You know, when he was working as a [professional]. He would have two or three screens going at the same time, complicated documents, flipping back and forth on the	Well, you know, it used to be that when I was working and before I had PD, I could get up and get dressed and be out the door in half an hour, you know, now it takes me longer but I used to do the same things. You know, so and

	phone with somebody, you know. And this is the guy now that I have to drive the train to help him understand what would have been so simple for him five years ago. Just, you know, it's just it's hard for me to watch this happen. But, you know, it is what it is.*	I'm still doing the same thing, but not at the same speed.*
Experiencing loss/losing something cared about (RE: IPD)	I think this might be his last year of golf. And that will be a problem. Oh, my gosh. I am really concerned about his mental health when that ends. And if it's as bad as I think it could be, we're going to need to get some help there, I think. Because that's just that's the thing that keeps that man going. It really, really has kept him going. He'll come home and he can't even move, because he's done so much, but he just loves it. If that's taken away by PD I think he could fall into some depression.*	Because in the summer I like to go play golf. But it's hard to do…ya know, I still am able to play golf, don't walk as far as I used to… I also used to sing in the church choir. But I can't do that no more. (crying) It's hard to sing when you're crying.*
Experiencing loss/losing something cared about (RE: Caregiver)	I can't wait to get him back to the senior center. That was you know, that would be what would happen. I get home from church, nobody's here, I would, you know, just veg out for a little while and I would bounce back a lot quicker. And then, you know, he'd show up at 3:30. And by that time, I'm probably sitting here with class and prepping some dinner and good. I don't have that anymore. It's just, it's just harder. I don't bounce back as quick. We used to go fishing all the time. You live on a lovely lake and that's normally what you want to do. And he just doesn't seem like he has the desire to do it anymore. But one night I was so bored. It was like nothing, nothing. For how long? And I actually got up several times and sat on the deck. It was a beautiful night. "We should be out fishing (laughs) not sitting here watching the ballgame. Not that I don't enjoy our times, but I just think that we're missing so much.*	I was a band director. I used to play in the community bands and about four years ago I dropped out, because of my physical limitations. I don't have enough breath control to play the musical phrases the way they're supposed to be. I have to breathe more frequently than the music would allow me to. And that was, uh, the section that I was in, there were four of us in the first section. And all four of us were high school band directors, so it was very competitive and um, I just couldn't compete anymore. And I didn't wanna, I didn't watch some kind of a charity thing where they just put me somewhere in the band.*
Losing strength/ground	Well, he's already admitted that he thinks that things are getting worse, especially when he doesn't feel really good at different times, and the fact is that he doesn't have the stamina to do anything. So, we went for a walk one night and he just took his cane, and we stopped several times, and he leans on his cane…We only got just right around the corner a little ways, like we normally would have walked a lot further. But it seemed like it was a chore for him.*	I resigned myself to, the fact that I'm never going to regain the strength that I had, I'm never going to regain the stamina I've had. I look back over the last five years and I've had blood pressure problems, uh, stamina problems... All kinds of physical problems. And I just don't see coming back to anything near what I was.*
Worry	Sometimes even getting up out of the chair, and going to the restroom and back again it seems like it's getting harder and harder for him to walk. He walks stooped over and uh. So	Well, I think she's concerned... that I'll have medical issues from working too hard. And I'm concerned with-for her about that too. I'm afraid she's going to have a heart attack and

	I think that's our biggest worry, is that it is getting worse. And we know it's not going to get better. That's just, you know, we can hope it, it doesn't.	she's she's afraid I'm going to have a heart attack.*
Burden or onus	I made the decision, but he had previously made the decision not to have a G tube and I did everything in my power to respect his decision… That yeah, that's tremendous pressure…It's big, it's...because I'm the medical person in my family, I always get to make these decisions [begins crying].. I don't wanna make this decision anymore… So this is my biggest long-term problem. I don't have to face it today, but it's out there… I have cried a lot of tears over it, but it's not something that you can really even share easily with your family with your children. I mean, it's mine.*	Well, they haven't so far cause CG seems to be holding up pretty well as far as what she feels her role as caregiver is. I'm feeling funny about it, 'cause I feel it getting more and more of a burden. But we do have long term care insurance and financially I'm not so worried as I am about the timing of the whole thing.*
Angry, annoyed, irritated	I've almost got to rehearse the conversation. So I try and give it because otherwise he gets real frustrated with me if he isn't understanding anymore, … and then he gets frustrated with me because he yells at me and he says, "Yes, well you gotta explain it in the way that I can understand it". And I'm like, "You know, and you've done it three times that you haven't gotten it right yet". It's like, I'm trying, but I just don't know what the verbiage is that he's going to understand what to me is a crystal clear sentence. But then when he's sitting in his chair, he'd be content to sit and read all day long. And sometimes I feel I want to say something to him. It's almost like I'm interrupting, you know, he'll still look down on his book. And I'll say, "Are you listening to me?" Then he'd say, "Yeah I'm listening." Sometimes I wonder.	Well, I think [she] comes to the table trying to make things better for me. But in doing that, I think she may feel that she's getting a little too bossy about the whole stuff and she gets some vibes from me that she shouldn't be sticking her nose in my business and that kind of stuff, so very often times, now I can't say very often, but sometimes I get a little irritated and that makes her work just that much more difficult. A lot of times my anger is not at her but it's at the disease but I know I've got nowhere else to uh, to uh place it. And so when I was trying to listen to what the [class] leader was showing and was talking to us about, you know, I was trying to do those things. She would stop me or would say to me, you know, you're supposed to lift your knee higher you know, things like that. She would give me suggestions. And it would get in between what the leader is trying to tell the group and what I was trying to absorb, because I don't have very good hearing anymore, in my one ear for sure.
Sadness or depression	Yeah, at least we've made such a great team and it's just it's hard for me because that that's that's the hardest thing for me right now is the guy used to know has really changed. He doesn't see it, but I do know and I'm seeing this this falling off and it's just really, really hard.*+	Regarding his emotion dysregulation: You know, whenever I talk about Parkinson's, it just come out without any provocation at all, you know. So I don't know, it's just part of having Parkinson's. You lose control of that. There's a medication you could take that would curtail it a little bit. But, you know, it cuts off the highs and lows. I don't like that.*+
Watching from behind	On his second trip in [to the house], I noticed that he knocked into the door jam, and then he knocked into the other one. It was like then I just dropped what I had, and grabbed him, because he was weaving. So, I guess I've kind of gotten used to **watching him from behind.**	Well, I think she's concerned... that I'll have medical issues from working too hard. And I'm concerned with-for her about that too… I'm afraid she's going to have a heart attack and she's afraid I'm going to have a heart attack. I tell her to stop and rest and she keeps going. She tells me to stop and rest.+

	All I had to do was worry about my rehab and when I could get back to the church to do that in the morning and then, you know, walk in and the afternoon and night and go pedal bike I don't think without that I would have I would have been as good as I am. IPD was very supportive while I was doing that, too, kind of keeping an eye on me and once in awhile go "don't overdo it".*	Everything she has to do is, she certainly can't do it anymore. That's a concern. Well, I don't know what else to do. You know, we try and work together so that we're both safe.*
Uncertainty of the future	I think the short term is keeping him on track and trying to help him get stronger. The longer term is our life situation…and wondering, you know, where is it going to end and how is it going to end? Yeah, because I don't know and we might not know…There is no crystal ball."*+	I feel that it's not fair for her to have to deal with my, with my symptoms. With, with things the way they are, but she does and..well, I say she didn't bargain for that. So there's a big question mark there as far as what the future holds for me and sometimes worries me, 'cause I don't want the care portion of it dumped on CG.*
Doing things together	We used to go fishing all the time… But one night I was so bored. [I said to him], "We should be out fishing (laughs) not sitting here watching the ballgame. Not that I don't enjoy our times but I just think that we're missing so much…So I must have said that so the next morning he said, "you want to go fishing?" And I said, "yeah". Twice in a row we went fishing. But that's what we have to do, to get out and do things that we used to enjoy.*+ You know, finding things that we could do together I think would be so good for us. We walk, it's along a country road, so we have to walk single file and drag the dog along, it's meant to be, I don't know, side by side. But, you know, I just think the camaraderie thing is something we have never really been able to build.*	Well, we virtually do everything together. I mean, we do the, the fun things, we do the chores around the house, all though she doesn't let me do a whole lot, around the house. It's alright if I go out and rank the lawn, though. But, I try and vacuum the house but, she doesn't let me sometimes. (sniffles)*+ I guess I'm not, um... (pause). I'm not going I will not come up with a lot of things that we do together other than just the routine things like went to, going to a show, going to out to eat once in a while and those kind of things, and um, I don't think at this point they haven't interfered with our, our uh, working or being together.*
Belonging	I promised him that I would be his partner in this years ago, and I think that I have. I think I've been an equal partner…I'm ready to commit to this for another seven years, if that's what it takes. I'll be here for the whole ride…I just love this man so much. He's been my heart and soul for 50 years.	CG and I have gone through more than 50 years of marriage and three kids very well, I think. We work together as a team and we put it together and for the most part, it, it was a lot of fun looking back at it..and it still is. But the Parkinson's makes it a lot harder.*
Key: * indicates quotes from the same dyad; + indicates quotes repeated elsewhere to denote overlapping concepts		

4.2.3 Theme 3: Participation in Exercise – "Staying Strong = Staying Healthy"

To better understand how the threats of PD motivated the dyads to engage in behavioral change, the discussions pivoted to exercise. As would be anticipated with most conversations involving physical activity, the dyads brought up a number of barriers and facilitators. For the participants of this study, references to facilitators outnumbered the barriers. All four dyads had experience with engaging in physical activity. Most participants noted the predominant motivators to address the challenges and threats of PD were either that exercise was important to their physical and mental health or engaging meant "*staying strong = staying healthy*".

<u>Barriers to Exercise</u>

Among the barriers to exercise for the dyads, environmental factors, weather, PD symptoms, and caregiver health conditions dominated the list of impediments to participation.

> **CG:** *The road will get to be sheer ice before winter is done, and that's not safe for him.*
>
> **IPD:** *But on the other hand, you know, the reason the exercise bike works is that I don't fall from that. You know, if I were outside walking or you have to have the walker with me or take a risk of falling and that risk goes away with the exercise bike.*
>
> **CG:** *He and I tried doing tai chi in the summer of 2019 down at the senior center. And I had to quit because of my left leg. They did a thing where it was like you had to do this all day. You were just going to the left…go to one side. I said, "I can't do that" you know, "when are you going to go to the right"? "Well, in a week or two we get to it". That was it. And I was not going to go back there. I was hurting so bad by the end of the class. I said, no, I can't do that anymore.*

Surprisingly, caregiving responsibilities did not come up often enough to merit a separate subtheme of barriers. However, motivation, or a lack thereof, was a recurrent theme for CGs, as well as IPDs.

> ***CG:*** *Well, I went through a program right after I had my open-heart surgery. And they've had me walking on a treadmill and they have an exercise bike, which I did that. But after I recovered, it seemed like I was thrown right back into my daily routine of housework, cooking, cleaning, everything else. And so, for a while I did walk on the treadmill but I kind of lost interest in that too. And I know I should probably be out biking or doing something. But most of the time I feel that I gain so much exercise bending around and gardening, pulling weeds and that kind of stuff that I never really got into a regular exercise program.*

> **IPD:** *Sometimes for no good reason I just, uh, sort of skip these things outside of the medication portion of it and don't do the voice training, don't do the uh physical exercise. You'll say, but what good is this [exercise] gonna do? I'll do this in another hour. I'm tired right now. I'm gonna go to take a nap. Just finding ways to, uh, get around it. That's part of the depression medication. That's sort of the attitude that I started taking the depression medication.*

Another subtheme that was discussed by all four dyads, was the conflict that arose between partners over participating in exercise. The following dyad exemplifies how the progression of PD and personal factors get in the way of the dyad exercising together:

> **CG:** *One thing he basically told me a couple of years ago, he had some exercise from his therapist that were very similar to the ones for my back. And my back was acting up a little bit. And I said, oh, good, we can do the exercises together. He said, "Nah, I won't exercise with you, you're too competitive…When walking became my PT, he tried to [join me] for a while, but I needed to walk at a pace he couldn't.*

> **IPD:** *Well, we used to walk a lot. You know I'm not going to take a walk, but it's just not convenient. That's too slow for her anyway.*

Facilitators of Exercise

Interestingly, for the participating dyads in this study, there were more references to facilitators of exercise than there were barriers. Among the facilitators most commonly noted were the types of exercises or physical activities that each individual enjoyed participating in, and the reasons they cited for the enjoyment.

> **CG:** *With Aqua Zumba, I mean, it was my joy. Just moving your body. And it was wonderful doing it in the water. But, you know, I'm in the sunshine in the pool and all that was just glorious. But I love to dance and the feeling of moving your body and the rhythm.*

> ***IPD:*** *I'm a very competitive guy and I like to excel at the activities, even physical activities that I participate in. The exercise group helps me do that, because I put a lot more intensity, I feel, into my workout than most of the other people there and it makes me feel good that, at least in that group, I'm regarded as being an over achiever.*

> ***CG:*** *We did go to boxing together, and umm…But I, it's a very therapeutic group, and not just in terms of the exercise, but in terms of people with the same mindset. (CG#001)*

Receiving encouragement was noted by seven out of the eight participants. CGs typically mentioned their role in trying to provide encouragement. Although it was predominantly considered a motivating factor, it was also noted as a hindrance.

> **IPD:** *She always encouraged me to bike and to do the Big and Loud program, and now I started on the loud part of that big and loud. And she encourages me then.*

> **CG:** *I thought that would be how we would interpret it that I was trying to, you know, pressure, him into doing things. I would tease him and try to get an interest in doing something, but when he would say no, I'm not. I'm not ready for that, And I would just back off.*

Support was also valued when it was provided by others external to the dyad.

> **IPD:** *I think that was one of the things that I actually look forward to [with an in-home cycling program]...I had some really great people that were working with me on the other end. And so, that was always fun and it made the time go by in a hurry. It's strange, but I never looked at the biking part as important as the contact and the discussions I had with the other people that supervised me. And I know that the biking was important, but I always thought the personal thing was more important.*

> **CG:** *[My doctor] said, you know, "walk walk walk, pedal, pedal, pedal" we were at the assisted living center that was just up the block from our house here, well, we were rebuilding the house from the fire, and so they had a bike there and I biked a lot and I walked, and, you know, got better.*

Experience with Exercise

Another significant facilitator or antecedent of exercise for all dyads was their experience with physical activities, with the top three most-referenced subthemes inclusive of doing PD-specific therapy and rehabilitation exercises, past participation in exercise, and engaging in physical activity together.

> **IPD:** *I try to do a, uh, if everything is going as I'd like to, I take a, uh, voice training, speech training, swallowing training over the internet, which usually takes about half an*

hour. I have some exercise programs I can either access on the internet, or in the uh....what I carried over yet from the [program name] activities that I did before.

CG: *I've had a number of rehabs on shoulders, so I do a set of exercises with weights and therabands with the shoulders, and I was recently diagnosed with osteoporosis, so I've picked up some weight exercises that I'm doing there, as well. And I've done some back rehab exercises. At this point, I'm not doing them because really I'm not that bad with the fact that I feel like I need to do them, but that's pretty much the kinds of things that I do, walking, biking and then some indoor exercises. I do some stretching in order to maintain the flexibility that I do have, it took a while after my leg thing.*

CG: *We kind of had our routine in the house where we had two staircases, one that goes down to the basement and one that goes upstairs. And so we had this route that we would walk through the house and we'd stop at these stations and do our exercises and then we both do a staircase and he'd go down and I'd go up in the next way. I would smack hands in the living room and then I'd go down and he'd go up.*

IPD: *We used to go golfing together. She would walk along, and I would play golf and, you know, but we shared the time of together.*

Staying Strong = Staying Healthy

When asked how their worries and concerns about PD affected their willingness to exercise, either independently or as a dyad, many of the IPDs and CGs focused on the importance of exercise to their physical and mental health, and how engaging in physical activity meant "*staying strong = staying healthy".*

IPD: *It's important for me to keep up my health because we lean on each other. And actually I'm concerned that if something happens to her if she has a fall, that I won't be able to pick up her slack because we've been through that once (crying)… Back in 2018,* *she slipped on the ice and broke her femur. And she was home for about a week…..You know, we try and work together so that we're both safe.*

CG: *And he doesn't like it when I when I'm hurting. So if I have exercises that I'm supposed to do for back rehab or like the leg rehab, he's very supportive of that. Obviously, we wanted to get me back so I can function.*

CG: *I think you need to stay as physically capable, the longer he can help take care of himself and be as strong as he can be, because I won't be able to lift him in and out of chairs, my back and my knees and everything, I'm just not able to do that kind of thing.* ***So the longer he can keep strong. It means that the longer I feel like he is going to live.*** *and he is going to be able to not be dependent and he does not want to go away to an assisted living or anything like that. So, yeah, I mean, he's certainly not there yet. I think it will slow down the progression. And I just think it will make him feel happier and more accomplished, more upbeat and more competent physically and mentally.*

CG: *In the words of one caregiver, when asked what she did to take care of herself, "[Exercise] is one of them. I can't take care of him when I'm not strong. So, staying physically strong helps me emotionally, as well. I know it helps him…Keeping him on track for the physical, you know get back in shape, get strong…Um, reclaim whatever you can."*

IPD: *Her partner with PD echoed her thoughts, "Unless I keep up with my [exercise], I'm finding out that with Parkinson's, unless you keep up with doing it on a daily basis and on an intense basis, it just gets, it just gets worse."*

For this final subtheme of the importance of exercise to physical and mental health, the fourth dyad once again differed from the others. The CG discussed the implications of exercise for both herself and the IPD. She commented, *"I think the more you do it [exercise]…the more you can do it. And it makes you feel so much better about yourself and your abilities."* As for the importance of exercise to her spouse, her comments are included above and relate to him staying ‘*physically capable…more upbeat…and more competent.’* In contrast, the IPD limited his response to noting the importance of exercise to his own health. However, it should also be noted that he ended the conversation somewhat abruptly due to factors external to the interview, but relevant to the dyad’s family dynamic.

Table 7 – Theme 3: Saturation grid of themes for exercise participation.

Themes & Subthemes	# of References	CG 01	IPD 01	CG 02	IPD 02	CG 03	IPD 03	CG 04	IPD 04
Effects on Exercise Participation *Dyad – “Staying strong = staying healthy”*									
• **Barriers:**									
○ Citing barriers – Environment, time, weather, safety, etc.	90*	X	X	X	X	X	X	X	X
○ PD Sx or CG health as a barrier	44*	X	X	X	X	X	--	--	--
○ Motivation as something needed to participate	37*	X	X	--	--	X	X	--	X
○ Conflict (or agreement) between partners	27	X	X	X	X	X	X	X	X
• **Facilitators:**									
○ ID’g types liked/disliked	105*	X	X	X	X	X	X	X	X
○ Citing facilitators – Enjoyment, looking forward, social aspects, competition, belonging, etc.	102*	X	X	X	X	X	X	X	X
○ Receiving encouragement or support	59*	X	X	X	--	X	X	X	X
○ Belonging	17	X	X	X	X	X	X	X	X
• **Experience with exercise:**									
○ Doing rehab exercises or therapy	93*	X	X	X	X	X	X	X	X
○ Participating in the past	98*	X	X	X	X	X	X	X	X
○ Participating together	81*	X	X	X	X	X	X	X	X
○ Participating alone	62*	X	X	X	X	X	X	X	X
○ ADLs as exercise	24	X	X	--	--	X	--	--	--
○ Readiness or contemplating participation	45*	X	--	X	X	X	--	X	X
○ Modifying for self or partner	16	X	--	X	--	X	--	--	--
• **Staying strong = staying healthy**	55*	X	--	X	X	X	X	X	X
○ Important to physical/mental health and staying on track	66*	X	X	X	X	X	--	X	--

Key: * indicates themes for which quotes are provided in Table 8; - indicates a negative effect of the subtheme

Table 8 – Theme 3: Quotes reflecting participation in exercise.

Themes & Subthemes	Caregiver Quotes	Individual with PD Quotes
Effects on Exercise Participation	*"Staying strong = staying healthy"*	
Citing barriers – Environment, time, weather, safety, etc.	The road will get to be sheer ice before winter is done, and that's not safe for him	You know, if I were outside walking or you have to have the walker with me or take a risk of falling. Only go [walking] as long as we could when the roads got slippery. Then we stop. And then when the roads cleared up of snow and ice we started up again.
PD Sx or CG health as a barrier	IPD and I tried doing tai chi in the summer of 2019 down at the senior center. And I had to quit because of my left leg. They did a thing where it was like you had to do this all day. You were just going to the left…go to one side. I said, "I can't do that" you know, "when are you going to go to the right"? "Well, in a week or two we get to it". That was it. And I was not going to go back there. I was hurting so bad by the end of the class. I said, no, I can't do that anymore.*	But on the other hand, you know, the reason the exercise bike works is that I don't fall from that. You know, if I were outside walking or you have to have the walker with me or take a risk of falling and that risk goes away with the exercise bike.*
Motivation as something needed to participate	Um…and he hasn't had the motivation to exercise and workout…So for him not to be exercising, this is the man who was all-state in football, when he was in high school. He's been an athlete all his life. Yeah, so for this man not to want to go start exercising again. I've tried to tease him into it and stuff and he just wasn't hearin' it.* Well, I went through a program right after I had my open heart surgery, and they've had me walking on a treadmill and they have an exercise bike, which I did that. But after I recovered it seemed like I was thrown right back into my daily routine of housework, cooking, cleaning, everything else. And so for a while I did walk on the treadmill but I kind of lost interest in that too. And I know I should probably be out biking or doing something. But most of the time I feel that I gain so much exercise bending around and gardening, pulling weeds and that kind of stuff that I never really got into a regular exercise program.*	Sometimes for no good reason I just, uh, sort of skip these things outside of the medication portion of it and don't do the voice training don't do the uh physical exercise. You'll say, but what good is this [exercise] gonna do? I'll do this in another hour. I'm tired right now I'm gonna go to take a nap. Just finding ways to, uh, get around it. That's part of the depression medication. That's sort of the attitude that I started taking the depression medication.*+ Well if I'm doing exercises in the house. I'm not really motivated to do it. I have to push myself quite a bit to do it.*
Conflict (or agreement) between partners	One thing he basically told me a couple of years ago, he had some exercise from his therapist that were very similar to the ones for my back. And my back was acting up a little bit. And I said, oh ,good, we can do the exercises together. He said, "Nah, I won't	Well, we used to walk a lot. You know I'm not going to take a walk, but it's just not convenient. That's too slow for her anyway.* So she did feel like she knew more about it [the boxing class] than I did. And I guess I was

	exercise with you, you're too competitive… When walking became my PT, he tried to [join me] for a while, but I needed to walk at a pace he couldn't.*	concerned with what the leader was trying to tell us to do. And it was hard enough for me to do that without having her trying to tell me to do it differently. So anyways, we kind of worked that out pretty much now, so.
ID'g types liked/disliked	I like yoga and Tai Chi in particular. Um, I think those are my two favorites. The um, I did some Pilates that kind of repetitive, but then I think about it, and yoga and Tai Chi are kind of repetitive too. I don't know. Maybe pilates is too much work. I like programs that are full body, that you're moving every part of your body.	I think that was one of the things that I actually look forward to [with the in-home cycling program]...I had some really great people that were working with me on the other end. And so, that was always fun and it made the time go by in a hurry. It's strange, but.I never looked at the biking part as important as the contact and the discussions I had with the other people that supervised me. And I know that the biking was important, but I always thought the personal thing was more important.
Citing facilitators – Enjoyment, looking forward, social aspects, competition, etc.	With Aqua Zumba, I mean, it was my joy. Just moving your body. And it was wonderful doing it in the water. But, you know, I'm in the sunshine in the pool and all that was just glorious. But I love to dance and the feeling of moving your body and the rhythm.	I'm a very competitive guy and I like to excel at the activities, even physical activities that I participate in. The exercise group helps me do that because I put a lot more intensity I feel into my workout than most of the other people there and it makes me feel good that, at least in that group, I'm regarded as being an over achiever.
Belonging	We did go to (name of studio) boxing together, and umm…But I, it's it's a very therapeutic group, and not just in terms of the exercise, but in terms of people with the same mindset.	She's certified to work with people with Parkinson's disease. And that's really good. And also knows how to handle people, and make people feel good. And that's really good too so.
Doing rehab exercises or therapy	I've had a number of rehabs on shoulders so I do a set of exercises with weights and therabands with the shoulders, and I was recently diagnosed with osteoporosis, so I've picked up some weight exercises that I'm doing there, as well. And I've done some back rehab exercises. At this point, I'm not doing them because really I'm not that bad with the fact that I feel like I need to do them, but that's pretty much the kinds of things that I do, walking, biking and then some indoor exercises. I do some stretching in order to maintain the flexibility that I do have, it took a while after my leg thing.	But I've taken a number of those courses through the local hospital. They have a department, and so I'll keep those sheets they give me for different exercises and work at those once in a while… I took the Big Program while still working two years ago. And that was one of the therapy groups that I was involved with. The individual came out to the house and we worked on those programs.
Participating in the past	No I can't really say we did much of exercise at all, we used to walk there too. Just the two of us, but. But otherwise, we never went to... Well, I shouldn't say, I shouldn't say that. I did go to some, um, through work sometimes the office girls would get together and we'd go to some place for an exercise program, but not anything that I did very long.	Before I had Parkinson's disease late in my employment, I started working out at the Y by myself 'cause I was just getting too out of shape sitting behind the desk the whole time and I had very good luck doing that. But even that gets old after awhile.
Participating together	We kind of had our routine in the house where we had two staircases, one that goes down to the basement and one that goes upstairs. And so we had this route that we would walk through the house and we'd stop at these stations and do our exercises and	We used to go golfing together. She would walk along, and I would play golf and, you know, but we shared the time of together. And this past year, we didn't do too much. That is just a matter of timing, I guess. I'm

	then we both do a staircase and he'd go down and I'd go up in the next way. I would smack hands in the living room and then I'd go down and he'd go up.	trying to think of other things that we would do, you know?
Participating alone	I really like the recumbent bike because this way I can if I can do it, if I don't do it for a long time, like some people get on it for 30 minutes, I'll bike for 10, 12 at the most. But, you know, I enjoy doing it. It gives me a chance to get my legs stretched out at night and when I get home after dinner. Also had some blood sugar control, so they don't end up in the range we don't want to be.	I try to do a, uh, if everything is going as I'd like to, I take a, uh, voice training, speech training, swallowing training over the internet, which usually takes about half an hour. I have some exercise programs I can either access on the internet, or in the uh....what I carried over yet from the [program name] activities that I did before.
Receiving encouragement or support	I thought that would be how we would interpret it that I was trying to, you know, pressure, him into doing things. I would tease him and try to get an interest in doing something, but when he would say no, I'm not. I'm not ready for that, And I would just back off. From others: He said, you know, "walk walk walk, pedal, pedal, pedal" we were at the assisted living center that was just up the block from our house here, well, we were rebuilding the house from the fire, and so they had a bike there and I biked a lot and I walked, and, you know, got better.	She always encouraged me to bike and to do the Big and Loud program, and now I started on the loud part of that big and loud. And she encourages me then.
Readiness or contemplating participation	OK, that was great, you know, but it was just like I said it was just the stars aligned in the right time at the right place for IPD when he was like, OK, I could probably do that might, that might work for me. Yea, with rehab it just has to be that way. And now if he decides and this is the thing, I think if he decides to stay in that group, I think it will help him.*	No that was CG's sister is one that has uh Parkinson's disease. A family member was the one that suggested that I, she suggested that I-why don't you come over and look at what we do? You know, I don't need to participate. Just come and stand and stand or sit and just to see what goes on. So after she encouraged me for a month or two or I never quite got around to doing it. But I finally did it. So that's how I got into it.*
Staying strong = staying healthy	I think the short term is keeping him on track and trying to help him get stronger. The longer term is our life situation…and wondering, you know, where is it going to end and how is it going to end? Yeah, because I don't know and we might not know…There is no crystal ball. So being as strong as he can is really important, and it's important that I stay strong "cause I can't help him if I don't.*+ I think you need to stay as physically capable, the longer IPD can help take care of himself and be as strong as he can be, because I won't be able to lift him in and out of chairs, my back and my knees and everything, I'm just not able to do that kind of thing. So the longer he can keep strong. It means that the longer I feel like he is going to live...I think it will slow down the progression. And I just think it will make him feel happier and more accomplished, more	Part of my physical exercise back when I was doing the boxing class, where you go through some of the boxing moves and stuff. I have a speed bag down in the basement of our condo and I used to be able to work on speed bag pretty well, but unless I keep up with my [exercise], I'm finding out that with Parkinson's, unless you keep up with doing it on a daily basis and on an intense basis, it just gets, it just gets worse.*

	upbeat and more competent physically and mentally.	
Important to physical/mental health and staying on track (IPD)	Short term...Keeping him on track for the physical, you know get back in shape, get strong...Ummm reclaim whatever you can.*	Now I've been out of that environment for a year almost, well for a year and uh I think my because of that lack of competitiveness and lack of regular, intense five day a week out of seven, I've lost a bit, or lost a lot of my physical and mental abilities that I had a year ago.*
Important to physical/mental health and staying on track (CG)	I can't take care of PD, when I'm not strong; and I've lost a lot of ground in these past few months. And, um, you know I have some things that I like to do. I know that I can do if I know that, If I know that I have the time for it like on a yoga class. So staying physically strong helps me emotionally as well. He doesn't he doesn't like it when I when I'm hurting. So, if I have exercises that I'm supposed to do for back rehab or like the leg rehab, he's very supportive of that. Obviously, we wanted to get me back so I can function.*	It's important for me to keep up my health because we lean on each other. And actually I'm concerned that if something happens to her if she has a fall, that I won't be able to pick up her slack because we've been through that once (crying)…Back in 2018, she slipped on the ice and broke her femur. And she was home for about a week. Yeah, and then we had a fire.*+
Key: * indicates quotes from the same dyad; + indicates quotes repeated elsewhere to denote overlapping concepts		

4.3 Quantitative Results

4.3.1 Self-Reported Measures

Four IPDs and three CGs completed the SRMs (Table 9). Mean MDS-UPDRS scores for Parts I and II were 11.75 +/- 6.70 points and 14.75 +/- 2.99 points, respectively, indicative of moderate disease severity (Martinez-Martin et al., 2015). Mean QOL scores for IPDs, as measured by the PDQ-39 were 23.23 +/- 6.21 points. CGs' mean QOL scores were 36.32 +/- 8.11 points on the PDQ-Carer. PASCQ results found that two individuals were in the pre-contemplation stage for PA, three in contemplation, one in preparation, and one in maintenance. On the PASE, participants reported engaging in different levels of PA from walking to strenuous activity, performed as infrequently as 1-2 days/week and up to 5-7 days/week. Six out of the seven reporting participants indicated they engaged in walking outdoors; three performed strength and endurance exercises, three indicated they participated in light recreation, and two noted strenuous recreation.

Table 9. Questionnaire data for individuals within dyads.

	Dyad #001		**Dyad #002**		**Dyad #003**		**Dyad #004**	
Assessment	CG	IPD	CG	IPD	CG	IPD	CG	IPD
MDS-UPDRS, part I	-------------	13	-------------	2	-------------	17	-------------	15
MDS-UPDRS, part II	-------------	18	-------------	16	-------------	11	-------------	14
PDQ-Carer or PDQ-39 SI	27.81	27.03	43.96	22.66	37.19	14.84	-------------	28.75
PA Stages of Change	Cont	Main	Prep	Cont	PreC	Cont	-------------	PreC
Types of Weekly PA & Number of Times/Week (PASE)	Walking *(5-7d/wk)* Strength *(1-2d/wk)*	Walking *(5-7d/wk)* Strength *(5-7d/wk)* Strenuous *(5-7d/wk)*	Strength *(3-4d/wk)* Strenuous *(5-7d/wk)*	Walking *(1-2d/wk)* Light *(3-4d/wk)*	Walking *(5-7d/wk)* Light (1-2d/wk)	Walking *(1-2d/wk)*	-------------	Walking *(1-2d/wk)* Light *(3-4d/wk)* Strenuous *(3-4d/wk)*

Key: **PDQ-39 SI**, Parkinson Disease Questionnaire-39 Summary Index and **PDQ-Carer SI** for PD-related QOL in the IPD and CG, respectively; scores range from 0 (no problems) up to 100 (maximum level of problems). **MDS-UPDRS Part I – Mentation, Behavior, & Mood**, Movement Disorder Society Unified Parkinson Disease Rating Scale, **MDS-UPDRS, Part II – Activities of Daily Living** for PD symptom presentation and disease severity; scores range from 0 to 52 for each of the parts, or 0 to 104 for both parts combined, where scores of 52 (for Part I or II separately) and 104 (for both parts) indicate the most severity. **PASCQ**, PA Stages of Change Questionnaire assigns one of five stages of change: 1) PreC = precontemplation (no intention to change), 2) Cont = contemplation (thinking about change), 3) Prep = preparation (intending to take action to change), 4) Act = action (modifying behavior), and 5) Main = maintenance (sustained behavior change) **PASE**, Physical Activity Scale for the Elderly, type of leisure time activity includes walking, light sport or recreation, moderate sport or recreation, strenuous sport or recreation, and strength and endurance. Frequency of an activity category includes never, seldom (1-2 days/week), sometimes (3-4 days/week), or often (5-7 days/week).

4.3.2 Canadian Occupational Performance Measure

All eight participants completed the COPM prior to beginning the main portion of the semi-structured interviews. The typical length of the COPM interview was 45 minutes to 1 hour. IPDs predominantly identified their top three problem areas as being related to PD symptoms, or the effects of symptoms on daily occupations. In contrast, CGs placed the highest priority on their caregiving role, with their own self-care and leisure activities being of secondary and tertiary importance. All eight individuals identified either strength and stamina or exercise as a top-ranked problem area of occupational performance. (See Table 10 for a listing of the top three self-identified performance problem areas from the COPM.) One individual did not provide satisfaction or performance scores due to confusion over the rating process; he expressed frustration over having to repeat the scoring more than once. As such, we truncated the COPM after he completed the rankings of his problem areas by importance.

Table 10. Participant top three self-identified occupational performance problem areas and related satisfaction and performance responses from the Canadian Occupational Performance Measure.

ID	Identified Occupational Performance Problem 1	Perf	Sat	Identified Occupational Performance Problem 2	Perf	Sat	Identified Occupational Performance Problem 3	Perf	Sat
IPD1	Swallowing	2	2	Fine motor movements	4	4	Loss of strength	5	2
IPD2	Moving safely around house	8	10	Golf	4	8	Driving	9	7
IPD3	Consistent exercise	4	2	Playing in band	3	1	Bladder control	8	5
IPD4	Walking	NR	NR	Self-care and appearance	NR	NR	Medication management	NR	NR
CG1	Caregiver responsibility	9	7	Confidence in physical	5	8	NR	-	-
CG2	Classes	2	1	Walking outside	1	5	Alone time (more)	2	3
CG3	Caregiving	8	8	Getting out and doing things	7	6	NR	-	-
CG4	Strength/stamina to caregive	9	7	Having help/social support	2	3	Less pain-physical/ mental	4	3

Key: Perf - Performance; Sat - Satisfaction; NR - Participant did not provide a response

Discussion

Engaging in exercise and physical activity offers several beneficial effects for individuals living with PD, including remediated motor and non-motor symptoms (Fox et al., 2018; Goodwin et al., 2008), improved occupational participation and performance (Foster et al., 2014), and enhanced QOL (Rafferty et al., 2017). Often overlooked for participation in physical activity interventions, though, are the spouses and family caregivers, who could potentially derive physical and psychosocial benefits from co-participating in exercise with their care recipients (Doyle et al., 2020). For PD care dyads, it is not well understood how the progression of the disease, and the perception of it as a threat to the well-being of the dyad influences their willingness to participate in physical activity. This exploratory descriptive study employed the theoretical model of interdependence with communal coping to investigate factors that may predispose PD care dyads to engage in exercise. Semi-structured interviews were conducted with IPDs and CGs and supplemented by descriptive quantitative data derived from self-report measures. Three major themes were identified: 1) Progression of Parkinson Disease, 2) Perception of PD as a Threat, and 3) Factors Influencing Participation in Exercise. Taken together, the perceived threat of PD influences the dyads to participate or consider participating in exercise, because “staying strong = staying healthy.”

The themes and subthemes were largely supported by the SRM data, such that the IPDs were in presumptive mid-stage of the disease with bilateral involvement and postural instability; their spouse CGs were living with multiple co-morbidities. Both members of the dyad reported moderately compromised QOL due to the progression of the disease. Members of all four dyads indicated problems with occupational performance due to physical limitations or loss of strength and stamina that could be improved through participation in physical activity; yet the IPDs engaged in exercise more frequently than caregivers. However, both members of the dyad had experience—past and present—with participating in physical activity, either independently or together as a couple; and two out of three CGs and three out of four IPDs were in a stage of change suggesting likelihood of future engagement in physical activity. The discussion that follows will compare the qualitative themes and quantitative results, placing both in the context of the available literature to suggest considerations for designing and implementing exercise interventions for PD dyads.

5.1 Throwing a Curveball at IPDs: The Heterogeneity & Unpredictability of PD

In the present study, IPDs were demographically homogeneous and appeared homogeneous in disease progression. They were all white males between 67 and 85 years old, and in mid-stage of the disease (Hoehn & Yahr, 1967). Their scores on the MDS-UPDRS parts I and II for mentation and ADLs (Goetz et al., 2008), respectively, indicated moderate disease severity (Martinez-Martin et al., 2015). PDQ-39 scores suggested compromised QOL. However, the population sampled for this study was remarkably heterogenous with respect to their progression of PD. Data from the questionnaires shows a disconnect between standardized reporting metrics and the data gathered during direct one-on-one interviews. Our findings from the interviews and the COPM provided greater insight into the variability of symptom presentation, daily experiences, and occupations of the participating PD dyads.

As emphasized by one IPD during the interview, *"I find that Parkinson's throws a new curveball at me just about every day. When I think I'm doing well with something, something else goes wrong."* This variability and unpredictability was not captured by the SRMs or the PD history and demographics form. In fact, all four IPDs neglected to mark the boxes indicating whether they had the cardinal symptoms of bradykinesia, rigidity, and tremor. Typically, these symptoms would be observed and scored as part of the MSD-UPDRS Part III, however, this portion of the assessment requires direct contact with the participant which was not done due to COVID-19 restrictions. Moreover, one CG noted several times throughout the interview that there are symptoms her spouse *"doesn't [like to] admit to."* In contrast, the interviews provided a rich data set that revealed the different motor and non-motor symptoms between IPDs, and the diverse ways that IPDs experienced and tried to control symptoms on a daily basis. Although there were some commonalities in the symptoms mentioned by the dyads—including the bilateral involvement and postural instability consistent with H&Y stage III—the interviews with each dyad revealed the heterogeneity of non-motor symptoms experienced by each of the

IPDs. While not all symptoms are reflected in the selected quotes presented in the results, a sampling of the non-motor symptoms noted by IPDs and CGs included problems with drooling, grip strength, emotion dysregulation, lack of motivation, loss of appetite, nocturia, nighttime hallucinations, depression, constipation, bowel obstruction, skin changes, problems with communication and handwriting, orthostatic hypotension, impulse control, and fatigue. Clearly, the composite scores of the SRMs are insufficient to reflect an individual's unique symptom profile, and the resultant effects of disease severity on daily living across the occupational domains (American Occupational Therapy Association, 2014).

The unpredictability of the disease, as reported in the present study, was echoed in two other qualitative studies. One study found that PD dyads were greatly affected by the daily variability of the disease, which limited their ability to plan participation in activities (Wressle, Engstrand, & Granerus, 2007). Similarly, Thordardottir et al. (2014), reported that participants with moderate disease severity emphasized the random timing of their motor symptoms, especially freezing of gait, dystonia, and falls, and that the unpredictability of those symptoms also negatively affected their daily activities and willingness to participate in occupations. The interview findings of the present study also complement those of Shulman et al. (2008), such that one or both members of the dyads indicated the IPDs were having more difficulties with ADLs and IADLs and needed more assistance from their CGs as they transitioned from H&Y stage II to III.

Although functional mobility and problems with driving were consistently mentioned across all four dyads in the present study, the IPDs differed in their abilities to perform other occupations. With regards to ADLs and IADLs, IPDs differentially noted problems with activities like dressing, personal hygiene and grooming, resting and sleeping, managing household finances, work, or leisure and social activities. The starkest contrast between two IPDs involved problems with swallowing. For one IPD, he had just recently begun to experience issues, but was still able to eat soft foods. However, for the other IPD, his inability to swallow (i.e. dysphagia) had recently progressed to a life-threatening situation, which required the placement of a gastrostomy tube (G-tube). In recalling the situation, his spouse said, *"He was so weak. You can't even imagine how weak he was…I mean he would've died. He was on the* *road."* Yet, none of these problems with disease severity or occupational performance and participation would have been detected, if only clinical measures had been used for evaluation. Overall, the progression of the disease, its unpredictability in symptom presentation, and the decrease in the IPDs' abilities to perform basic and complex ADLs resulted in a greater burden being placed on the caregiver, compromising their occupational performance, and quality of life.

5.2 Keeping All the Balls in the Air: The Effects of PD on CG Health & QOL

As their IPDs became less self-sufficient and more reliant on their spouses, the caregivers in this study were having to respond to the unpredictability of their IPDs' disease progression and symptom severity by endeavoring to manage additional tasks and responsibilities. This ultimately compromised their own health and quality of life. As one of our CGs noted several times, "*You just can't keep all those balls in the air."* The qualitative results of this study show an increase in burden and stress on the CG, along with poor health and diminished occupational performance and QOL, as reported in the quantitative measures.

The qualitative findings of this study are similar to those of Berger et al. (2019) and Prado et al. (2020) whose PD caregiver participants described their experiences as a "balancing act" either between providing additional care and letting go of prior roles and activities (Berger et al., 2019), or dividing their time between caregiving and self-care (Prado et al., 2020). However, where the caregivers in Berger et al. (2019) and Prado et al. (2020) discussed strategies that they employed to balance care of their spouses versus self-care, the CGs in the present study postponed healthcare appointments, risked injury to prevent their spouses from falling, and took on tasks that were not only contraindicated for their health conditions, but also beyond their physical capabilities. This subjugation of self was identified in another study of PD caregivers conducted by Bolland et al. (2015). Although the crux of the study was interested in examining PD caregivers' experiences with healthcare providers, the authors noted that their participating CGs felt like they were not entitled to have their own needs met, and that the focus of care should be on their partner with PD (Bolland et al., 2015). The results of the COPM also reflected the priorities for our sample of caregivers in that they placed the importance of their own self-care and leisure activities as subordinate to that of their caregiving role. This occurred despite caregivers being encouraged to think more holistically about their daily lives when identifying problematic areas in daily function.

The results of minimizing their own well-being may be a direct impact on caregiver health. Where only limited demographics and health information were reported in the aforementioned qualitative studies conducted with PD caregivers (Berger et al., 2019; Bolland et al., 2015; Prado et al., 2020), in the present study, our CGs had more chronic health conditions compared to their IPDs and had experienced more hospitalizations. Among the co-morbid health conditions of the three CGs reporting health histories in this study, they mentioned heart problems, diabetes, high blood pressure, stroke, thyroid problems, Crohn's disease, arthritis, low back pain, depression and anxiety, osteopenia and osteoporosis, and other musculoskeletal conditions. They also reported lower QOL scores than their IPDs.

Given that all the CGs in our study were female, gender effects may account for the results. In a cross-sectional study of PD dyads, spouse caregivers with significantly lower QOL tended to be female, older, with long-term health conditions, longer duration of caregiving, and those providing care for IPDs with mobility and cognitive impairments (Morley et al., 2012). Similarly, a longitudinal study conducted over 10 years by Lyons et al. (2009) reported that being a female spouse to an IPD was a predictor of increased strain. Lyons et al. (2009) concluded that female spouse CGs to individuals with PD are at increased risk for poor health outcomes. The results of the present study concur with Lyons' conclusion, but also support the value of collecting both qualitative and quantitative data to provide more definitive insights into the different experiences and health outcomes of PD caregivers.

5.3 Watching from Behind: Transformation of Motivation for Communal Coping

Few studies in the literature are available to examine the effects of physical activity for dyads of individuals with neurological disorders and their caregivers, fewer still for PD dyads; an even smaller portion of those studies are based on theory (Fakolade et al., 2020). The present investigation aimed to address the gaps in the literature by designing a qualitative study centered around a theoretical application specifically geared to dyads dealing with a health threat, such as PD. The interdependence model of communal coping and behavior change developed by Lewis et al. (2006) suggests that spouses and partners are more likely to engage in a behavioral change, like exercise, when they share similar concerns about the health threat, believe they can meet the challenge of it together, and transform their motivation from consideration of self to consideration of the affected partner or the relationship. Transformation of motivation is influenced by a number of predisposing factors, including how strongly the couple perceives the threat of the disease, their relationship, preferences for outcomes, communication style, and demographics. The present study was specifically focused on examining whether the progression of PD and the perception of it as a threat would elicit a transformation of motivation to engage in exercise.

Several subthemes emerged to support our second main theme of “The Perception of PD as a Threat”. Particularly compelling indicators of the perceived threat were the comments participants made about the uncertainty of the future: *“Wondering, you know, where is it going to end, and how is going to end? Because I don’t know and we might not know…There is no crystal ball…So being as strong as he can is really important, and it’s important that I stay strong ‘cause I can’t help him if I don’t.”* Although other studies have found uncertainty to be strongly associated with distress in PD caregivers (Hurt et al., 2017) and PD dyads (Sanders-Dewey et al., 2001), the authors only examined individual factors and coping strategies, and not the factors employed in a communal coping strategy involving behavioral change.

For three out of the four dyads in the present study, their transformation of motivation and communal coping was particularly evident when their comments reflected the efforts they would undertake to look out for each other’s safety. As one CG described it: “*I’ve kind of gotten used to watching him from behind”.* One could argue that the idea of “watching from behind” is a maladaptive behavior, suggesting hypervigilance, which was found to co-occur when caregivers neglected their self-care (Roland & Chappell, 2015). However, in the present study, the theme of “watching from behind” was also frequently noted by IPDs. For example, a similar sentiment was echoed by an IPD, who said, *"You know, we try and work together so that we're both safe."*

Another indicator of the use of communal coping by three of the dyads in the present study was the concurrence between the stories and sentiments relayed by IPDs and CGs within their respective dyad, and as seen in the tables displaying quotes representative of each theme. One such subtheme that presented strong support for transformation of motivation and communal coping was "belonging." Although the focus of this study was on a singular predisposing factor, namely the perception of the threat, for three out of the four dyads "belonging" applied to their commitment to each other and the relationship, which is another predisposing factor identified by Lewis et al. (2006) as being essential to transformation of motivation. One dyad expressed "belonging" in a particularly moving way: The CG said, *"I promised him that I would be his partner in this years ago, and I think that I have. I think I've been an equal partner…I'm ready to commit to this for another seven years, if that's what it takes. I'll be here for the whole ride…I just love this man so much. He's been my heart and soul for 50 years."* Two days later when we conducted the interview with the IPD, he said something very similar, *"She and I have gone through more than 50 years of marriage and three kids very well, I think. We work together as a team and we put it together and for the most part, it, it was a lot of fun looking back at it..and it still is. But the Parkinson's makes it a lot harder."* For the three dyads who expressed this sense of belonging, they also shared similar concerns about the threat of PD, the belief that they could meet the challenge together, and were motivated out of concern for the well-being of the IPD and their relationship. In short, they appear to meet several of the conditions suggesting they would be more likely to engage in a behavioral change, such as exercise.

In stark contrast to the three dyads, the fourth dyad did not meet the Lewis et al. (2006) criteria for transformation of motivation. Some key indicators were their discordant views of doing things together, the statements in which they minimized each other, the lack of expression regarding "belonging" within their relationship, and other home life circumstances that indicated high levels of dysfunction within the family dynamic. Moreover, the IPD was newly diagnosed; although, the dyad suspected that he had the disease for quite some time. He was also more resolved to having PD and indicated he wasn’t worried about what the future held for himself. Whereas her concerns revolved around him becoming more dependent upon her in the future. As such, several aspects of their interviews suggest they may be less likely to engage in a dyadic behavioral change intervention.

5.4 Staying Strong = Staying Healthy: Considerations for Dyadic Exercise

The research question for this study focused on how the progression of PD and the perception of it as a threat to the health and well-being of the care dyad influences participation in exercise. All eight participants noted the importance of exercise to their physical and mental health, which was related to the theme of “staying strong = staying healthy”. In the words of the CG whose transformation of motivation was strongly driven by the uncertainty of the future: “*Being as strong as he can is really important, and it’s important that I stay strong ‘cause I can’t help him if I don’t.*” Her partner said something similar: *“…unless I keep up with my [exercise], I’m finding out that with Parkinson’s, unless you keep up with doing it on a daily basis and on an intense basis, it just gets, it just gets worse.”*

5.4.1 Discrepancies between Intent to Exercise and Reporting of Participation

Despite participants noting the importance of exercise, there were incongruencies between their impetus for exercise, their stage of change for engaging in physical activity, and their actual participation. Only one IPD indicated being in the maintenance stage of regular exercise. The other two participants indicated they had no intention to participate. However, all seven participants who completed the PASE reported they had at least engaged in walking outdoors in the past 7 days; and six out of the seven had participated in some other form of light to strenuous physical activity. Interestingly, one IPD who noted on his PASE that he had walked outdoors, was also adamant about not walking: “*You know I'm not going to take a walk, but it's just not convenient.”* Similarly, when other participants reported frequency and duration of exercise, it revealed additional irregularities between their interviews, the PASE, and the demographic profile, particularly for CGs. The three CGs that completed both SRMs indicated they engaged in some form of exercise as often as 5-7 times per week; however, their demographics revealed a different picture. For the CGSs who reported exercise duration, one indicated zero minutes per session, and the other 15 minutes per session.

While it is possible that participants in this study did not consider walking to be a form of exercise, it is also not unusual for individuals, especially older adults to have trouble with recalling exercise activities. A study of veterans with PD and their partners found discrepancies between patient and proxy reports recalling exercise frequency (Fleming et al., 2005). If participants in the present study assisted each other with the exercise recall and reporting, it is possible that the individuals within the dyads may have over or under-reported. Another possible reason for the discrepancies in caregiver reporting of physical activity may be due to shortcomings of the PASE. Although question 9-d on the PASE asks whether the respondent engaged in caring for another person, a “yes” answer awards only a few points for the PA total value. Unfortunately, the PASE fails to recognize or award points for caregiving based on the types of caregiving responsibilities, number of days per week spent caregiving or the number of hours in each day dedicated to this occupation. We know that with PD, the intensity of disease-specific caregiving increases as the disease progresses, yet there are no physical activity measures that take this into account. Nonetheless, caregiving activities for an older adult, such as toileting, bathing, and transferring require considerably more energy and effort than cooking, feeding, or assisting with buttoning a shirt. As such, it is possible that the caregivers in the present study may have accounted for physical activities differently between the PASE and the exercise-related questions on the demographics form. Moreover, as previously mentioned, the activities associated with caregiving may require that caregivers do not get less physical activity (Fredman et al., 2006).

5.4.2 Barriers and Facilitators to Exercise: Confirming and Extending the PD Literature

Results of this study add to and extend the literature on barriers and facilitators of exercise participation in both IPDs and CGs. Barriers for IPDs have been more extensively studied, however, limited information was previously available for PD caregivers and the dyad, as a unit. Our findings align with other studies investigating barriers in IPDs (Afshari et al., 2017; Ellis et al., 2013; Schootemeijer et al., 2020), but also those exploring barriers in caregivers for individuals across a variety of disease pathologies (Cao et al., 2010; Etkin et al., 2008; Hirano et al., 2011; Marquez et al., 2012). Similar to these earlier studies, the participants in our study noted environmental factors, weather, fear of falling, low expectations for deriving benefits, fatigue, mood disorders, PD symptoms, and CG health conditions that resulted in pain during exercise.

In contrast, participants in this study were far more likely to bring up things that facilitated their participation in exercise, which included past and present positive experiences, as well as preferred types of exercise, and doing PD-specific exercises for IPDs and rehabilitation therapy for CGs. During the interviews, the participants also emphasized the psychosocial benefits they derived from exercise, such as feelings of joy, self-efficacy, being with people of the same mindset and experiences, contributing to the group, and feeling good physically. Many of these facilitators were noted in three other studies, one qualitative study conducted with PD dyads (Prieto et al., 2021), a mixed methods study with PD caregivers (Prado et al., 2020), and a study for advanced cancer dyads that employed the interdependence model with communal coping (Ellis et al., 2017).

5.4.3 Barriers and Facilitators for Dyads

This study also contributes to the limited information available on barriers and facilitators to PD dyads participating in exercise together. Motivation was one barrier mentioned by both IPDs and CGs. Although the subtheme did not achieve full saturation in the context of exercise, it merits further exploration. This finding was supported by Afshari et al. (2017), who found that low motivation was frequently cited in low-exercising IPDs. Given that apathy is a non-motor symptom of PD, overcoming a lack of motivation to exercise may be especially challenging when it is experienced by both members of a dyad. However, the authors of Afshari et al. (2017) also reported that one effective method for inspiring IPDs to engage in exercise involved external motivation coming from either a neurologist, personal trainer, or a loved one. Insights from the present study also supported the value of external support and may account for the subtheme of motivation failing to reach full saturation. Several participants commented that giving and receiving encouragement from their partner or others was particularly instrumental in facilitating exercise.

Doing things together as a couple, may also be both an indicator of transformation of motivation, as noted in the discussion of the second major theme, but also an antecedent of exercising together. All four dyads noted doing things together, as well as participating together in physical activity. For the CGs of the present study, they also expressed a desire to do things together with their spouses again, often as a way to recapture the past while holding onto what was possible in the present. One CG's comment was particularly poignant: *"But that's what we have to do, to get out and do things that we used to do...Not that I don't enjoy our times, but I just think we're missing so much."* Findings of the present study suggest the four dyads may have a preference for co-participating in exercise together.

In contrast, a subtheme emerged around conflict between partners over participating in exercise together. Oftentimes, the conflict centered around PD symptoms and progression of PD. In addition to the example highlighted in the results narrative, one IPD noted he did not like being told by his spouse when to do his exercises; and another noted his frustration at having his spouse assist him during an exercise class when he was trying to focus on what the instructor was saying. Similarly, CGs noted conflict. One CG indicated she wanted her spouse to join her on walks but preferred he use a scooter so he could keep up with her. Another CG expressed frustration at her spouse when she tried multiple times to get him to go fishing with her instead of reading or watching television. While many studies have identified PD symptoms as a barrier to exercise for the IPD, the results of this study may be unique in that it points to the symptoms as a source of conflict potentially preventing both members of the dyad from engaging in exercise.

5.4.4 Considerations for Dyadic Intervention Design

In summary, when adapting a dyadic approach to exercise interventions for IPDs and their CGs, several factors should be taken into consideration. The progression of PD, heterogeneity of symptom presentation and disease severity may require the tailoring of adaptive interventions to meet the varying needs of IPDs. Given the ever-increasing caregiving demands on their spouse CGs with their own compromised health, it is equally important to develop interventions that avoid placing additional burden and onus on the caregivers, while creating opportunities for them to prioritize their own health and well-being. Although not all dyads may be well-suited for co-participating in exercise together, for those dyads who are willing to engage in behavioral change together, it may be especially useful to capitalize on the facilitators of exercise and underscore how physical activity is beneficial to both partners. In addition to emphasizing the possible benefits, the interventions should address the potential for conflicts that may arise from a dyadic approach. Possible solutions include offering separate interventions for IPDs and CGs, or including behavioral therapies that enhance relationship functioning and foster communal coping.

5.5 Implications & Future Directions

5.5.1 Implications

To the best of this author’s knowledge, this was one of the first studies to employ the interdependence model of communal coping to investigate how the impact of PD progression and the perception of it as a threat on the well-being of PD care dyads influences their participation in exercise. Our findings from two of the key themes are unique and add to the literature on PD dyads and communal coping. Firstly, the idea of “watching from behind”, as it relates to looking out for each other’s well-being may be an important indicator of communal coping and transformation of motivation. Secondly, “staying strong = staying healthy” may be a broadly applicable health promotion theme to encourage both members of a PD care dyad to engage in exercise. Given the limited application of the theory in physical activity interventions for PD dyads, to date, this study may prove useful in identifying additional factors that influence dyadic participation in exercise. Moreover, the information gleaned from this study will help in hypothesis generation, and design and implementation of future exercise and PA interventions to improve the well-being of both members of PD care dyads. If beneficial and feasible, similar health promotion programs—guided by interdependence and communal coping theory—could be widely adopted, not only for PD dyads, but also for dyads living with other chronic and progressive diseases.

Beyond the application of the theory, this study has important implications to research and intervention design, as well as clinical practice, and policy development. Engaging in physical activity as a meaningful occupation can improve the health and well-being of both members of a PD care dyad. Yet, the existing literature indicates spouse caregivers of IPDs have been largely overlooked for participation in exercise interventions. Given the medical model of disability that focuses on providing person-centered care for the individual with a given pathology (World Health Organization, 2002), it is understandable why researchers and clinicians develop treatments specifically for IPDs. However, individuals rarely experience disease in isolation. As such, the medical model often disregards the caregiver, who is an integral member of the dyad and often a key determinant of an intervention’s effectiveness. This study may help to shift research and clinical practice paradigms by demonstrating the value of a family-centered approach to better understand how the progression of PD and the perception of the disease as a threat to both members of the dyad influences behavioral change.

By taking a family-centered approach that includes caregivers and emphasizes a biopsychosocial model of care that combines the medical approach with individual and social factors (WHO, 2002), interventions may be more effective at remediating motor and non-motor symptoms and slowing disease progression for the IPD, while concurrently improving physical and mental health, enhancing occupational performance and participation, as well as quality of life and well-being for IPDs and CGs. However, as we learned from the Doyle et al. (2021) systematic review, it is insufficient to merely include caregivers in interventions. Instead, it is essential that researchers design studies for PD care dyads in which the methodologies specifically plan for and include the caregiver. Additionally, larger randomized control trials will be needed to compare investigations of dyadic exercise versus caregiver-only and IPD-only exercise. As part of the efforts to include caregivers, it will also be important to take the time to understand their interests and needs. For example, caregivers in this study expressed a need for respite, psychosocial and behavioral support, and education to better understand the disease and improve their caregiving skills to prepare for the progression of their loved ones' symptoms.

The aforementioned examples of caregiver interests reinforce the need for the development of policies, like the Caregiver Advise Record Enable (CARE) Act (NAC & AARP, 2015) which aims to provide caregivers with instruction on medical tasks to be performed in-home following their loved ones' hospital discharge. However, as identified by Leighton et al. (2020), significant institutional barriers exist to implementing such policies, and integrating caregivers in clinical care and research. One way to overcome barriers is through the use of tools, like the Care Partner Hospital Assessment Tool (CHAT), which aims to engage caregivers in a brief discussion to assess their needs for information and skills training to handle their caregiving tasks for older adults (Fields et al., 2021). A tool, such as CHAT, could be adapted for use in the development of physical activity interventions to assess caregiver needs and interests related to exercise programming, combined with psychosocial and educational components. From a broader public health perspective, bolstering the physical and psychosocial well-being of PD care dyads, through family-centered physical activity and multi-component interventions, will help contain the escalating costs associated with PD in the United States, which are currently estimated to exceed $34 billion (Kowal et al, 2013) and expected to reach $50 billion in the U.S. by 2040 (Huse et al., 2005). In short, policies, tools, research funding, and public discourse are needed to develop and implement community-based and in-home physical activity interventions for PD dyads.

5.5.2 Future Directions

Working with my mentoring team, we have identified the next four projects to develop from this dissertation. Firstly, we will conduct interviews and collect SRMs from an additional 4-6 dyads to further explore the themes that emerged from this study for the purpose of hypothesis generation toward developing and implementing a future dyadic intervention. Given that exploratory descriptive studies lend themselves well to a mixed methods approach (Bradshaw et al., 2017), we may rescope the study to a hypothesis-driven mixed methods and employ the statistical analysis used in the Actor-Partner Interdependence Model (Cook & Kenny, 2005). Secondly, we will utilize the interviews from this group of dyads, plus the additional ones to investigate the effects of other predisposing factors on communal coping and engaging in exercise as a behavioral change; results will be used to develop a predictive tool to identify couples who are best suited for dyadic physical activity versus solo exercise interventions. Thirdly, future graduate students working in Dr. Kristen Pickett's Sensory Motor Integration Lab will work to develop a culturally sensitive and appropriate Spanish translation of the questions and interview guides employed for this study, in order to explore similar research questions in more diverse populations. Lastly, and most importantly, findings from this study are already being used to develop and implement a physical activity intervention addressing the needs of rural-dwelling dyads of individuals with PD and their CGs.

5.6 Strengths, Limitations & Personal Reflections

5.6.1 Strengths

Among the many strengths to this study are the insights we gained from pairing the qualitative and quantitative findings. Doing so, enabled us to compare and contrast differing data approaches. The strengths of conducting semi-structured interviews as a qualitative data collection method are the thoughtful reflection and exchange that occurs between an individual participant and the interviewer, and the efforts to independently address each interviewee's perspectives. Although it was not possible to conduct face-to-face interviews due to the COVID-19 pandemic, completing the interviews over video conference and telephone allowed the participants to choose convenient interview times. Careful protocols were established to help build rapport and to ensure privacy. Offering multiple options to complete the interviews enabled the study to reach participants while still obtaining high quality data (Khalil et al., 2021; Mealer & Jones Rn, 2014; Novick, 2008).

Additionally, we took several steps to address subjective biases including: 1) we collected multiple data sources including the semi-structured interviews, the COPM, and the SRMs; 2) qualitative data were analyzed by two independent researchers; and 3) results were cross checked with debriefings immediately following each interview, field notes and key impressions, as well as brief narratives, memos, and observations. Additionally, two members of the study team (one of whom is an expert in developing and implementing in-home, activity-based interventions for older adults and people with PD and one an expert in health promotions developing and evaluating behavioral interventions for community members with chronic conditions living in rural settings) reviewed the analysis to ensure the themes and supporting quotes were in alignment with the research question.

Moreover, the use of the COPM in this study provided additional valuable insights into each participant's self-reported occupational problem areas. Without the information gleaned from the COPM, we may not have captured the priority held by all participants to improve strength and stamina—an occupational performance area that is readily enhanced by participation in physical activity and exercise. Our interview findings, coupled with the validated SRMs, demonstrate how composite scores of clinical metrics fail to accurately characterize an individual's symptom presentation, and highlight the importance of conducting interviews, like the COPM, to enrich our understanding of an individual's unique experience for the purpose of improving outcomes for both members of the dyad. Most importantly, the underlying value of the qualitative exploratory descriptive approach allowed us to meet participants where they are, so that we can better design and implement intervention studies that best serve their needs, both as individuals and as dyads.

5.6.2 Limitations

Although this study had its limitations, we worked to address them through rigorous methodologies. Power and sample sizes are difficult to determine in qualitative research. My co-mentors on this study—based on their previous experience—determined a priori that four dyads would allow for examination of preliminary themes and ideas that may address the underlying question around future intervention design. This sample is limited, not only in size but in demographic considerations, because all IPDs were in H&Y stage 3 presenting with bilateral involvement and postural instability. As such, results may not represent the views of dyads in different stages of the disease. Additionally, our sample consisted of all white, midwestern, English speaking older adults. To that end, the implications of this study are limited in their generalizability across the larger population.

When interpreting our approach to the qualitative data collection, limitations around bias and focus of the questions should be considered. As noted in the section on study strengths, we took several steps to address bias. The self-reported measures used in this study were validated, however, there is a risk for information bias, particularly recall and responder bias, which may have played a role in the discrepancies observed between the PASE, the demographics, and the interviews. Similarly, the interviews conducted via web-conferencing may have elicited the Hawthorne effect in that this was a study about exercise. As such, when participants were asked to tell us what they do to take care of themselves, many were likely to respond “exercise”, which was clearly not reflected in the SRMs or the demographic data. Additionally, my roles as a caregiver, mother and graduate student combined with the impact of COVID-19 on the emotional and psychological wellbeing of all participants and members of the research team should certainly be considered when interpreting these findings.

Lastly, our choice to narrow the focus of this project to only one predisposing factor from the interdependence model of communal coping (Lewis et al., 2006) limited our insights on other factors, such as the couple’s preferences for outcomes, relationship functioning, gender, and communication styles. Although the narrow lens was a valuable approach to examine a specific aspect of the model and will help to advance the literature on dyadic PA interventions, it left us with unanswered questions about how couples, similar to the fourth dyad, would best be served by a dyadic intervention, or whether they are good candidates for one, at all. However, our interviews did include questions about marital and relationship functioning, which will serve as the basis of a future paper and will inform the development of future interventions.

5.6.3 Personal Reflections

Having come from a research training background focused solely on quantitative methodologies, conducting this exploratory descriptive study gave me a greater appreciation for the value and deeper insights that come with qualitative methods. I was both humbled and honored by the individuals who participated in this study. Not only did they give of their time, but they gave of themselves by opening a window into their lives, their joys, their sorrows, and their fears of an uncertain future. And they did this in the midst of a global pandemic. For all of us, participants and research team members, alike, the social isolation, disruptions to our daily activities, pandemic related stress, and significant changes to our support structures have had a profound effect on our lived experiences. As it related to conducting the interviews, on the one hand hearing participants' stories and personal experiences was very difficult emotionally; but on the other hand, the human connection was also meaningful and uplifting. As a caregiver, myself, who at the time of the interviews was also undergoing considerable strain due to a family and personal crisis, I found myself relating to and empathizing with the caregivers in ways I hadn't experienced previously in other settings. Given the many opportunities to inflect my personal biases into the data analysis, I was especially impressed by the sheer magnitude of the efforts undertaken by all the members of the research team to ensure the rigor, trustworthiness and confidence in the findings. As noted in the acknowledgments, I am grateful to the many individuals who contributed to this research endeavor.

5.7 Conclusion

Dyadic interventions may be especially relevant when each member of the dyad is motivated to respond to the health threat of PD for the benefit of one another and their relationship. Findings from this study highlight the extent to which the progression of the disease impacts the everyday occupations of PD dyads, and how their worries and concerns influence their participation in exercise.

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Review Article

Systematic Review of Exercise for Caregiver–Care Recipient Dyads: What Is Best for Spousal Caregivers—Exercising Together or Not at All?

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Abstract

Background and Objectives: Though exercise for care recipients receives considerable emphasis, few dyadic studies focus on caregivers. This systematic review identified dyadic exercise interventions, which measured outcomes for older adult caregivers. Studies that met inclusion criteria were examined to better understand whether caregivers derived greater benefit from exercising with care recipients, or not exercising at all.

Research Design and Methods: PRISMA guidelines were followed to identify quantitative studies of dyadic exercise interventions in which caregivers enrolled with care recipients, and either coparticipated in exercise; or while their care recipients exercised independently, caregivers received a separate, nonexercise intervention or usual care (UC). To be included, studies had to measure physical or psychosocial outcomes for caregivers. Study quality was assessed via the Downs and Black checklist.

Results: Eleven studies met inclusion criteria. In six, the dyad exercised; in five, care recipients exercised while caregivers received a separate program, or UC. Results suggest that caregivers may improve both psychosocial and physical health when exercising together with care recipients. Caregivers who did not exercise but received a separate, nonexercise intervention, such as support, education, or respite, showed psychosocial benefits. Those who received UC were less likely to derive physical or psychosocial benefits. Included studies were fair to good quality with moderate to high risk of bias.

Discussion and Implications: Often examined secondarily, caregivers are overlooked for participation in interventions with care recipients. This analysis suggests that caregivers may benefit from dyadic interventions in which they either exercise together with their care recipients or receive a separate nonexercise intervention or respite.

Keywords: Family caregivers, physical activity, Psychosocial health, and physical health.

Background and Objectives

As many as 36 million people in the United States provide unpaid, informal care for older adults (Giovannetti & Wolff, 2010; Riffin, Van Ness, Wolff, & Fried, 2017). Among informal caregivers, 47% are adult children and 11% are spouses or partners of the care recipients (NAC &

AARP, 2015). Compared to adult child caregivers, spouses and partners (hereafter referred to collectively as spouses) typically provide more hours per week of care (Pinquart & Sorensen, 2011), and feel a greater sense of obligation to be carers (Riffin et al., 2017; Wolff, Spillman, Freedman, & Kasper, 2016).

Higher-hour spousal caregivers report worse physical health, greater stress, anxiety, and depression, a diminished sense of well-being and self-efficacy (Pinquart & Sorensen, 2003; Riffin et al., 2017), and poorer performance of activities of daily living (Jenkins, Kabeto, & Langa, 2009). Additionally, longer-term spousal caregivers report progressively higher levels of burden (Swinkels, Broese van Groenou, Boer, & Tilburg, 2019). They are also at greater risk of morbidities including frailty (Dassel & Carr, 2016), hypertension, cardiovascular disease (Capistrant, Moon, Berkman, & Glymour, 2012), dementia (Dassel, Carr, & Vitaliano, 2017), and premature mortality (Fredman et al., 2008, 2010; Schulz & Beach, 1999).

Moreover, older spousal caregivers who have provided care for a longer period of time are less likely to engage in activities that improve their health (Queen, Butner, Berg, & Smith, 2019). Taken together, the increased risks associated with being spousal caregivers not only affects their own health, but may ultimately limit their ability to continue providing care to loved ones. As such, it is essential to identify, evaluate, design, and implement effective interventions that address caregiver health and well-being; and physical activity-focused interventions are one area of research that merits further exploration.

Physical activity (PA) interventions, including exercise, have proven efficacious for older adults; reducing their risk of chronic diseases, preserving functional capabilities, enhancing cognition and psychological well-being, and enriching community and social engagement—all of which are essential to healthy aging among an ever-increasing older adult population (Bauman, Merom, Bull, Buchner, & Singh, 2016). Similarly for caregivers of adults with a variety of chronic diseases, recent reviews suggest that PA has a favorable effect on burden (Lambert et al., 2016; Orgeta & Miranda-Castillo, 2014), and some psychosocial outcomes (Lambert et al., 2016; Loi et al., 2014); but results were less robust for physical health (Lambert et al., 2016). Spousal caregivers cite a number of barriers to PA including their own mental and physical health (Cao et al., 2010; Etkin, Prohaska, Connell, Edelman, & Hughes, 2008; Hirano et al., 2011a and b; Marquez, Bustamante, Kozey-Keadle, Kraemer, & Carrion, 2012), perceptions of increased burden due to caregiving (Hirano et al., 2011b), and limited time to engage in their own self-care (Etkin et al., 2008). Interestingly, some spousal caregivers indicate they do not enjoy exercising alone (Cao et al., 2010). Many are interested in physical and leisure time activities they can engage in with their care recipients (Cao et al., 2010; Malthouse & Fox, 2014; Van't Leven et al., 2013) to enhance their time together, and gain social participation and support (Anton, Partridge, & Morrissy, 2013).

Dyadic exercise interventions, in which both caregivers and care recipients are involved, may enhance social participation and overcome other barriers to engaging in PA, while benefitting both partners. Spousal dyads can mutually influence mental and physical health, including perceptions of well-being and quality of life, development of depression, hypertension, and cardiovascular disease (Meyler, Stimpson, & Peek, 2007); and facilitate adoption of preventative health behaviors (Falba & Sindelar, 2008; Meyler et al., 2007; Pai, Godboldo-Brooks, & Edington, 2010). Chronic disease and functional limitations in one member of a spousal dyad often result in decreases in PA between both members of the couple (Li, Cardinal, & Acock, 2013). However, spouses who remain physically active in the face of a partner's disease can positively influence physical activity maintenance for the dyad (Li et al., 2013). This is more commonly seen in wives who were physically active prior to their partner's disease (Li et al., 2013). Dyadic interventions also have the potential to ameliorate spousal caregivers' restricted social participation (Baanders & Heijmans, 2007; Riffin et al., 2017; Wolff et al., 2016), and weakened relationships with friends, relatives, and especially their spousal care recipients (Anton et al., 2013; Baanders & Heijmans, 2007; Davis, Gilliss, Deshefy-Longhi, Chestnutt, & Molloy, 2011).

Lending support to the positive impact of dyadic interventions targeting couples living with chronic illnesses, a 2010 review and meta-analysis examined a range of behavioral and psychosocial, couple-oriented interventions compared to patient-only interventions (Martire, Schulz, Helgeson, Small, & Saghafi, 2010). Programs such as education, partner support, relationship counseling, coping, problem-solving skills, and health behaviors were among the included dyadic interventions, in which care recipients and caregivers either participated together, or each member of the couple received treatments separately. For both types of dyadic interventions, 80% of studies yielded promising results over and above patient-only interventions for care recipients who experienced greater improvements in pain and depression, as well as marital relationships. In contrast, only 25% of the reviewed studies indicated similar improvements to caregivers' well-being and relationships; the remaining studies either found no significant differences (30%) or did not report on caregiver outcomes (45%).

A 2016 review of PA interventions primarily targeting only caregivers (for care recipients with Alzheimer's, cancer, stroke, and mental illness) reported on two dyadic exercise studies that also found improvements in caregiver psychological health, as well as enhanced functional fitness in both members of the dyad (Lambert et al., 2016). However, in one study, it was unclear whether dementia caregivers were coparticipating or receiving separate treatment (Canonici et al., 2012); in the other study, stroke caregivers were coparticipating, but authors reported only descriptive statistics (Marsden et al., 2012).

Given the limited evidence for dyadic exercise interventions, especially for the effects on caregivers, this systematic review contributes to and expands the body of literature by identifying additional dyadic exercise interventions for caregivers and their older adult care recipients. Specifically, the purpose of this systematic review was to examine whether caregivers realize greater physical and psychosocial health and well-being benefits when: (a) the caregiver–care recipient dyad enrolls and exercises together, or (b) the dyad enrolls together, but then separates with the care recipient exercising and the caregiver completing a nonexercise intervention or usual care (UC). Based upon the studies that met the inclusion criteria, we examined the literature to better understand whether caregivers derived greater benefit from exercising with care recipients, or not exercising at all.

Methods

Methodological Structure

Based on the 2009 Checklist of the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) (Moher, Liberati, Tetzlaff, Altman, & Grp, 2009), we conducted a descriptive systematic review of the literature.

Eligibility Criteria

Studies

This review included randomized controlled trials (RCT), quasi-experimental, case–control, and cohort studies of dyadic exercise or physical activity interventions, in which adult caregivers of older adult care recipients were evaluated for physical and psychosocial indicators of well-being. To be included, studies had to be published in peer-reviewed journals or in press. Excluded were systematic reviews and meta-analyses, descriptive or qualitative studies, meeting abstracts, conference abstracts, editorial introductions, letters to the editor, opinions, and position statements.

Participants

Targeted participants were informal, unpaid adult caregivers, which could include spouses, adult children, and family members. Studies had to define caregivers and their older adult care recipients with physical conditions, chronic diseases, and/or memory problems. Studies examining informal caregivers of infants, children, and adolescents, as well as paid and institutional caregivers were excluded. Caregivers had to be enrolled or participating with care recipients as a dyad; or they were required as part of eligibility criteria for care recipients to participate. Studies also had to provide demographic data for caregivers, which, at a minimum, needed to include gender distribution and average age. Outcome measures for caregivers had to be reported in the results of included studies.

Interventions

Included studies had to involve interventions using some form of physical activity or exercise, where according to Caspersen, Powell, & Christenson (1985), "PA is defined as any bodily movement produced by skeletal muscles resulting in energy expenditure; and exercise is a subset of PA that is planned, structured and repetitive to improve physical fitness" (Caspersen et al., 1985). (For the purpose of this review, the two terms are used interchangeably hereafter.) Mindfulness-based activities (e.g., meditation and breathing), pharmaceutical and surgical trials were excluded, unless part of a multicomponent physical activity intervention.

The intervention was required to target dyads in which: (a) caregivers and care recipients enrolled and coparticipated in exercise together (hereafter referred to as DyEx), or (b) the dyad enrolled together, but then separated or split into different groups, such that care recipients exercised, while caregivers received a nonexercise intervention or UC (hereafter referred to as DySplit). See Figure 1 for descriptive diagrams of DyEx versus DySplit. Interventions in which caregivers were involved primarily to assist care recipients with exercise were excluded.

Comparisons

Comparison groups were not required but could include other types of physical activity, psychoeducation, support groups, counseling, dyadic training (unrelated to exercise), nutrition, day care, or other single or multicomponent interventions. "Usual care" (UC) and "treatment as usual" were also accepted as comparison groups.

Outcomes of Interest

Outcomes of interest included caregiver physical health (e.g., heart rate, body mass, biomarkers), psychosocial health (e.g., depression, burden, strain), and well-being (e.g., quality of life, sleep quality), all of which could be primary or secondary as identified by researchers in the respective studies. At a minimum, studies had to use at least one standardized and validated outcome measure. For studies coreporting on care recipients, we also examined their physical, psychosocial, and well-being outcomes. Excluded were studies only reporting descriptive statistics.

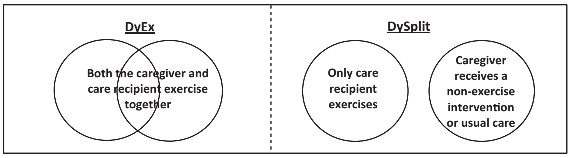

Figure 1. Descriptive diagrams of DyEx versus DySplit studies.

Information Sources and Search Strategy

Sources of Information

A search strategy was initially developed and executed in PubMed, then modified and conducted in Web of Science, CINAHL Plus (to include ERIC, SocINDEX Full, and SPORTDiscus), Cochrane Library, OT Seeker, Psych Info, and Scopus. The last search was run on April 17, 2017. Additional articles were identified during a limited literature update performed up to and including January 4, 2019, based on the published protocol and method papers found in the original search.

Search Strategy

To optimize search results, a combination of Medical Subjects Headings (MeSH) and field tags were used to exclude studies with infants or children, and to describe variations of key topics, namely caregivers, exercise, exercise movement techniques, and adults. Additionally, specific key words were used to describe typical exercise interventions for caregivers or older adult care recipients (e.g., walking, hiking, stretching, swimming, cycling, treadmill, strength and resistance training, yoga, tai chi, dance, and Pilates). See Table 1 for a sample search strategy. Only human subject studies using the English language were searched. To capture as many relevant articles as possible, no timeframe limit was imposed. The search yielded journal articles between January 1978 and April 17, 2017. Following completion of the searches, all references were uploaded to EndNote for further processing.

Procedures for Identification and Data Collection

Study Selection

Search results were compiled and uploaded to EndNote. Duplicates were eliminated using EndNote, and by culling through each title to search for juxtaposing of full names and initials. The review team of seven people included four graduate students and three faculty members. Articles were screened for inclusion first by title, then abstract, and then full text. At each stage of screening, the article (title, abstract, or full text) was independently reviewed by at least two reviewers. Three teams of two reviewers conducted the title search with each team member independently reviewing one third of all titles. Retained titles from each reviewer were recombined and redistributed to different teams for independent abstract review. Abstracts retained from each team member were again recombined and redistributed for full article review and data extraction. To avoid rejection of relevant articles, three independent reviewers each reviewed one third of the articles; and the first author reviewed all full-text articles. All articles stemming from a single study were assessed independently for inclusion. Interrater agreement was 78% on full-text articles. Regular arbitration meetings were held to establish consensus on acceptance and rejection of all articles. For those articles needing further arbitration, the full team was consulted and the principal investigator made final decisions.

Table 1. Sample Search Used in PubMed

1	(caregivers[mh] OR caregiv*[tw] OR carer[tw] OR care giver*[tw] OR informal care*[tw])
2	AND (exercise[mh] OR exercise[tw] OR "physical activity" OR "physical fitness" OR "leisure activity" OR walking OR hiking OR stretching OR swimming OR cycling OR treadmill OR "exercise movement techniques"[mh] OR yoga OR "tai chi" OR "tai ji" OR dance OR Pilates)
3	NOT (infant[mh] OR child[mh]) NOT (adult[mh])
4	Filters: English

Note: Adding "resistance training" as a MeSH [mh] or text word [tw] did not change the number of PubMed studies, because the term falls under the MeSH of "exercise." However, "resistance training" did increase the records sufficiently in other databases to merit adding it as a key term. MeSH = Medical Subjects Headings.

Data Collection Process

Using the 2011 Cochrane Handbook for Systematic Reviews of Interventions as guidance, a data extraction form was developed (Higgins & Green, 2011). Reviewers were trained and practiced using the developed form on three studies. Three reviewers each extracted data from one third of the full-text articles. To verify extracted data on included studies, four authors independently checked data, and then met to compare and develop consensus. All authors reviewed the final version of the evidence table before submission for publication. See Tables 2 and 3 for a full description of included data.

Assessment of Quality and Risk of Bias in Individual Studies

Given the diversity of the included research, we opted to use the Downs and Black checklist to provide a common scoring system for assessing quality and risk of bias in both nonrandomized and randomized control trials (Downs & Black, 1998). Question 27, which addresses statistical power, was modified from a possible score of five points to one point for analyzing and achieving adequate power or to zero points for no power calculations. Thus, studies are rated excellent (26–28), good (20–25), fair (15–19), and poor (≤14) (Chudyk, Jutai, Petrella, & Speechley, 2009). Regular meetings were held to establish consensus on scoring. No studies were excluded on the basis of score.

Data Synthesis

Given the heterogeneity of caregivers and care recipients, as well as included levels of evidence and methodologies, narrative synthesis was used to report results and discuss intervention effectiveness.

Table 2. DyEx—Characteristics of Included Studies in Which Both Members of the Dyad Exercised Together (*N* = 6)

Study	Participants	Caregiver interventions	Caregiver measures and outcomes	Care recipient interventions	Care recipient measures and outcomes
Badger et al. (2007) RCT Pre, post (6 weeks), F/U (1 month) *N* dyads = 96	**CG:** Partners (P), family, friends; *N* = 96 (71P-M/25F); age = 51.68 years **CR with breast cancer:** *N* = 96 (F); age = 54.11 years	**CG interventions:** Home via telephone delivery TIP-C: (*N* = 38) Telephone counseling and cancer education 6 weeks/1×/biwk/34 min/call EX: (*N* = 19) Self-managed walking 4×/week; and counseling calls 6 weeks/1×/biwk/11 min/call AC: (*N* = 30) Attention control printed info and calls; 6 weeks/1×/biwk/7 min/call	**Depression:** CES-D MEtime: All improved ($p < .001$) MEgrp: NS MEgxt: NS **CG anxiety:** Composite of 8 anxiety-related questions MEtime: All improved ($p = .02$) MEgrp: NS MEgxt: NS; trend ($p = .09$); TIP-C and EX improved at 6 weeks, all NS at F/U	**CR interventions:** Same as CG, different doses TIP-C: (*N* = 38) 6 weeks/1×/week/34 min/call EX: (*N* = 21) 6 weeks/4×/week and counseling calls 1×/week/11 min/call AC: (*N* = 33) 6 weeks/1×/week/7 min/call	**Depression:** CES-D MEtime: NS; trend ($p = .08$) for all to improve MEgrp: TIP-C highest depression, but improved ($p = .03$) from B/L to F/U MEgxt: NS **Anxiety:** Eight-question composite MEtime: All improved ($p < .001$) MEgrp: NS MEgxt: TIP-C ($p < .001$) and EX ($p = .01$) improved at 6 weeks only
Burgener et al. (2011) RCT and quasi-experimental Baseline, post-test (20 weeks) *N* dyads = 38	**CG:** Family members Multimodal-Dyad (MMD): *N* = 10 (6F/4M); age = 75.8 years Multimodal-CR (MMCR): *N* = 8 (5F/3M); age = 79.3 years Control: *N* = 14 (9F/5M); age = 74.6 years **CR with dementia:** early to middle stage (no other info)	**CG interventions:** Community MMD: (*N* = 10) CG chooses to exercise w/CR; Taiji, 20 weeks/3×/week/1 hr; and support group for CGs only; 20 weeks/biwk/1.5 hr MMCR: (*N* = 8) Only CR exercises, CG only attends support; same doses UC (CG only): (*N* = 14) UC plus educ; 20 weeks/bimon	**Stress:** RSS MMD vs MMCR: NS; trend ($p = .12$) for lower personal distress in exercising CGs Multimodal vs UC: NS **CG family relationship:** ECFR MMD vs MMCR: NS Multimodal vs UC: CG in multimodal fewer negative feelings toward CR ($p = 0.03$) All comparisons BtwGrp	**CR interventions:** Similar to CG Multimodal: Addition of CBT, w/cognitive training for CR only UC: Delayed intervention	CR outcomes described elsewhere
Lowery et al. (2014) RCT Pre, post (6 weeks), follow-up (6 weeks) *N* dyads = 131	**CG:** Partner/spouse ($p = 62.7\%$) Walking: *N* = 67 (50F/17M); age = 65.4 years UC: *N* = 64 (39F/25M); age = 60.9 years **CR dementia (1 min BPSD):** Walking: *N* = 67 (35F/32M); age = 79 years UC: *N* = 64 (39F/25M); age = 78 years	**CG interventions:** Home-based Walking: (N=59); 12 weeks/5×/week/20–30 min at RPE of 12–14; 6 weeks guided by therapist; 6 weeks independent UC: (*N* = 57)	**Burden:** ZBI, at 12 weeks walking decreased burden, UC doubled ($p = .01$) **Distress:** NPI-Q, NS **Mental health:** GHQ, NS **CG on CR QOL:** Dem-QOL, NS All comparisons BtwGrp	**CR interventions:** Same as CG Walking: (*N* = 59) UC: (*N* = 57)	**Behavior:** NPI-Q, NS **Health:** GHQ, NS **QOL:** Dem-QOL, NS All comparisons BtwGrp

Table 2. Continued

Study	Participants	Caregiver interventions	Caregiver measures and outcomes	Care recipient interventions	Care recipient measures and outcomes
Milbury et al. (2015) Single-arm Feasibility Trial Pre, post (5–6 weeks) *N* dyads = 15	**CG:** Spouse (*N* = 6), family member (*N* = 3), other (*N* = 6); *N* = 15 (6F/9M); age = 58.95 years **CR with lung cancer:** *N* = 15 (4F/11M); age = 62.16 years	**CG intervention:** Clinic-based Vivekananda Yoga: (*N* = 9); yoga exercises, breathing, relaxation, and meditation; 5–6 weeks/2–3×/week/60 min; home practice encouraged; printed materials provided	**Psychological distress:** BSI-18, NS depression (ES = 0.25); NS anxiety (ES = 0.03); NS somatization (ES = 0.06) **Fatigue:** BFI, NS (ES = 0.08) **Sleep:** PSQI, reduction in sleep disturbances (p = .02, ES = 1.01) **Health-related QOL:** SF-36, NS physical (ES = 0.50); NS mental (ES = 0.08) **Spiritual well-being:** FACT, NS (ES = 0.24) **Benefit finding:** BFCS, NS (ES = 0.12) **Emotional intimacy:** CLOSE, NS (ES = 0.07) All comparisons *t*-tests	**CR intervention:** Same as CG Vivekananda Yoga: (*N* = 9)	**Psychological distress:** BSI-18 Anxiety decreased (p = .04, ES = 0.81); NS depression (ES = 0.28); NS somatization (ES = 0.65) **Fatigue:** BFI, NS, (ES = 0.12) **Sleep:** PSQI, NS (ES = 0.36) **Health-related QOL:** SF-36, mental improved (p = .04, ES = 0.84); NS physical (ES = 0.15) **Spiritual well-being:** FACT, NS (ES = 0.31) **Benefit finding:** BFCS, NS (ES = 0.64) **Emotional intimacy:** CLOSE, NS (ES = 0.19) All comparisons *t*-tests

Table 2. Continued

Study	Participants	Caregiver interventions	Caregiver measures and outcomes	Care recipient interventions	Care recipient measures and outcomes
Milbury et al. (2018) Single-arm Feasibility Trial Pre, post (5–6 weeks) N dyads = 5	**CG:** Spouse (N = 3), sibling, adult child (N = 2); N = 5 (3F, 2M); age = 58.16 years **CR with high-grade glioma:** N = 5 (4F/1M); age = 51.94 years	**CG intervention:** Clinic-based Vivekananda Yoga: (N = 5); yoga exercises, breathing, relaxation, and meditation; 5–6 weeks/2–3×/week/60 min; home practice encouraged; DVD provided at week 5	**Fatigue:** BFI, NS (ES = 0.21) **Depression:** CES-D, improved (p = .08, ES = 1.04) **Report CR Sx severity:** MDASI, Improved perception of CRs' Sx (p = .05, ES = 1.25); NS total score (ES = .67); NS Sx interference (ES = 0.32) **Health-related QOL:** SF-36, NS physical (ES = 0.48); NS mental (ES = 0.64) **Sleep:** PSQI, NS (ES = 0.49) All comparisons t-test; authors set alpha p = .10	**CR intervention:** Same as CG Vivekananda Yoga: (N = 5)	**Fatigue:** BFI, NS **Depression:** CES-D, NS (ES = 0.59) **Sx severity:** MDASI, improved total score (p = .08, ES = 1.03); NS Sx inventory (ES = 0.81); NS Sx interference (ES = 0.79) **Health-related QOL:** SF-36, NS physical (ES = 0.07); NS mental (ES = 0.60) **Sleep:** PSQI; better sleep quality (p = .10, ES = 1.17) All comparisons t-test; authors set alpha p = .10
Winters-Stone et al. (2016) RCT Pre, post (3 months), F/U (6 months) N dyads = 64	**CG:** Female spouses; N = 64F Exercising Together (ET)Strength: age = 66.5 years UC: age = 69.7 years **CR-prostate cancer survivor:** N = 64M ET-Strength: age = 70.6 years UC: age = 72.9 years	**CG interventions:** University facility ET: (N = 32); progressive strength training with partnered aspects; 6 months/2×/week/60 min with 8–10 upper and lower body exercises/8–15 reps/ea/4%–15% body weight UC: (N = 32); at conclusion of study, received instructional video for home use and a workshop	**Body composition:** DXA ET gained lean mass (p = 0.05) **Maximal muscle strength:** 1RM ET improved upper body (p < .01), lower body (p < .01), and chair stand (p = .02), but NS for gait speed **Physical function:** PPB ET improved (p = .01) **Self-reported health:** SF-36 NS in physical health, mental health, or vitality/fatigue **Self-reported PA:** CHAMPS, NS All comparisons BtwGrp	**CR interventions:** Same as CG ET: (N = 32) UC: (N = 32)	**Body composition:** DXA, NS **Maximal muscle strength:** 1RM ET improved upper body (p < .01); but NS in lower body, chair stand, and gait speed **Physical function:** PPB, NS **Self-reported health:** SF-36, NS in physical health, or vitality/fatigue, but trend (p = .06) for improved mental **Self-reported PA:** CHAMPS ET more PA, UC decreased (p < .01) All comparisons BtwGrp

Key - General Abbreviations: B/L = baseline; BPSD = behavioral and psychological symptoms of dementia; CG=caregiver; CR=care recipient; F/U=follow up; PA=physical activity; RPE=rating of perceived exertion; Sx=symptoms; UC=usual care (also treatment as usual).

*Key - Outcomes & Measures Abbreviations:*1RM = 1-repetition maximum; BFCS = Benefit Finding in Cancer Scale; BFI = Brief Fatigue Inventory; BSI-18 = Brief Symptoms Inventory-18; CES-D = Center for Epidemiological Studies-Depression Scale; CHAMPS = Community Healthy Activities Model Program for Seniors; CLOSE = Perceived Closeness and Responsiveness Measure; Dem-QOL = Dementia Health-Related Quality of Life; DXA = Dual-energy X-ray Absorptiometry; ECFR = Elder-Caregiver-Family Relationship scale; FACT = Functional Assessment of Cancer Therapy; GHQ = General Health Questionnaire; MDASI = MD Anderson Symptom Inventory; SF-36 = Medical Outcomes Study 36-item Short-Form Survey; NPI-Q = Neuropsychiatric Inventory; PPB = Physical Performance Battery; PSQI = Pittsburgh Sleep Quality Index; RSS = Relatives Stress Scale.

Key - Statistical Tests Abbreviations: BtwGrp = between groups; ES = effect size; MEtime = main effect of time; MEgrp = main effect of group; MEgxt = effect of grp x time; t-test = paired t-test.

Table 3. DySplit—Characteristics of Included Studies in Which Care Recipients Exercised, and Caregivers Received a Nonexercise Intervention or UC ($N = 5$)

Study	Participants	Caregiver interventions	Caregiver measures and outcomes	Care recipient interventions	Care recipient measures and outcomes
Barnes et al. (2015) Pilot, non RCT B/L, cross-over (18 weeks), post (36 weeks) N dyads = 12	**CG:** Partners (N = 2M), Daughters (N = 9D); N = 11 (2M/9F) FM: N = 6 (5D/1M-P); age = 57.5 years UC: N = 5 (4D/1M-P); age = 54.6 years **CR with mild to moderate dementia:** N = 11 FM: N = 6 (5F/1M); age = 85.67 years UC: N = 5 (4F/1M); age = 81.6 years	**CG interventions:** Home Grp 1 FM: (N = 6 at 18 weeks, and N = 3 at 36 weeks); UC for CG, but instructors met with the dyad to provide exer instruction for CR and assess CR goals and interests; four in-home visits over 18 weeks, plus biwkly calls to CG for reporting of CR adverse events Grp 2 UC: (N = 4 at 18 weeks, and N = 6 at 36 weeks); biwkly calls for adverse events Cross-over design: From 1 to 18 weeks, Grp 1 in FM and Grp 2 in UC; from 19–36 weeks, Grp 1 in UC and Grp 2 in FM	**Distress:** NPI-Q BtwGrp: NS (ES + 0.21) w/iGrp1: NS (ES + 0.26) w/iGrp2: NS (ES + 0.49) **Burden:** CBI BtwGrp: NS (ES + 0.49) w/iGrp1: NS (ES + 1.92) w/iGrp2: NS (ES – 0.05) **CR Func'l Ability:** ADCS-ADL BtwGrp: NS (ES = 0.07) w/iGrp1: NS (ES 0.12) w/iGrp2: NS (ES – 0.31) **CR Behavior:** NPI-Q BtwGrp: NS (ES + 0.02) w/iGrp1: NS (ES + 0.59) w/iGrp2: NS (ES – 1.22) **CR QOL:** QOL-AD BtwGrp: NS (ES + 0.33) w/iGrp1: NS (ES + 0.50) w/iGrp2: NS (ES + 0.47) All BtwGrp comparisons at 18 weeks. For effect sizes, +Favors FM, –Favors UC, =Both groups same; authors defined ES ≥ 0.25 as clinically meaningful.	**CR interventions:** Adult day care Grp 1 Functional Movement (FM): (N = 6 at 18 weeks; N = 4 at 36 weeks); combination of physical therapy occupational therapy, yoga, Tai Chi, dance; 18weeks/2 days/week/45 min Grp 2 UC: (N = 5 at 18 weeks, N = 6 at 36 weeks); usual care of chair-based exercises, art, music; 18 weeks/2 days/week/20 min Cross-over design: same as CGs	**Physical function:** PPB and SFT **Lower extremity function** BtwGrp: NS (ES + 0.34) w/iGrp1: NS (ES + 0.25) w/iGrp2: NS (ES + 0.34) **Sit and reach** BtwGrp: NS (ES – 0.32) w/iGrp1: NS (ES – 0.49) w/iGrp2: NS (ES + 0.71) **Back scratch** BtwGrp: NS (ES + 0.35) w/iGrp1: NS (ES + 0.99) w/iGrp2: NS (ES – 0.40) **Mobility-8ft up and go** BtwGrp: NS (ES + 0.24) w/iGrp1: NS (ES + 0.29) w/iGrp2: NS (ES + 0.32) **Cognitive function:** ADAS BtwGrp: NS (ES + 0.76) w/iGrp1: NS (ES + 0.55) w/iGrp2: NS (ES + 0.38) **Quality of life:** QOL-AD BtwGrp: NS (ES + 0.83) w/iGrp1: NS (ES + 1.61) w/iGrp2: NS (ES – 1.06)

Table 3. Continued

Study	Participants	Caregiver interventions	Caregiver measures and outcomes	Care recipient interventions	Care recipient measures and outcomes
Lamb et al. (2018) RCT Pre, post (6 months), F/U (12 months) N dyads = 459	**CG:** Spouse (S), Adult Child (AC), or Other (O) Ex ± UC: N = 305 (218F/87M); 239(S), 55(AC), 11(O); age = 69.1 years UC: N = 154 (125F/29M), 117(S), 32(AC), 4(O); age = 70.2 years **CR with mild to moderate dementia:** Ex ± UC: N = 329 (195M/134F); age = 76.9 years UC: N = 165 (106M/59F); age = 78.4 years	**CG interventions:** Community and home Ex ± UC: (N = 258; 184F/74M) UC: (N = 129; 104F/25M) All CGs received UC	**Burden:** ZBI, NS **Health-related QOL:** EQ-5D, NS All comparisons are main effects at 12 months.	**CR interventions:** Same as CGs Ex ± UC: (N = 278; 112F/166M); cycling (25 min) and strength training (3 sets/20 reps), moderate to hard intensity, plus usual care; doses: (1) gym: 4 months/2×/week/60–90 min; (2) home: 4 months/1 hr/week; (3) postintervention home: 150 min/week with behavioral strategies UC: (N = 137; 51F/86M); usual care included clinical assessment, carer counseling, Rx treatments, brief PA advice	**Cognition:** ADAS, both groups declined, exer significantly worse ($p = .03$) **Praxis/memory/language:** ADAS, NS **ADLs:** BADL-proxy by CG, NS **Behavior:** NPI-proxy by CG, NS **Health-related QOL:** EQ-5D, NS **Quality of life:** QOL-AD, NS **Falls and fractures:** NS **6-min walk test:** 6MWD, Ex group improved by 18.1 m ($p = .001$); only tested in Ex group
Maci et al. (2012) Pilot RCT B/L, post (3 months) N dyads = 14	**CG:** Family members; wives (W), husbands (H), daughters (D), sons (S) PA ± Cog ± Soc: N = 7 (3W/3D/1S); age = 54.6 years UC: N = 7 (3W/2H/2D); age = 60.4 years **CR with Alzheimer's Disease:** PA ± Cog ± Soc: N = 7 (4F/3M); age = 75 years UC: N = 7 (4F/3M); age = 70.3 years	**CG interventions:** Respite PA ± Cog ± Soc: CGs received 12 weeks/3–4 hrs/day (15–20 hr/week); researchers transported CRs to and from gym setting UC: Usual care	**Burden:** CBI, PA+ improved ($p < .05$); UC worsened ($p < .05$) **Depression:** BDI, PA + improved ($p < .05$); UC worsened ($p < .05$) **QOL of CR:** QOL-AD, PA + improved ($p < .05$); UC worsened ($p < .05$) All comparisons w/iGrp.	**CR interventions:** Community PA ± Cog ± Soc: Physical activity (aerobic, balance, gait, coordination) at mild intensity, plus cognitive stimulation, and socialization; 12 weeks/5×/week/60 min (PA) + 60 min(cog) +60 min(soc) UC: Treatment as usual	**Cognitive:** MMSE, NS either group **ADLs:** NS either group **Executive function:** FAB, UC worse ($p < .05$); NS PA+ **Anxiety:** HAM, PA+ improved ($p < .05$); NS UC **Depression:** CSDD, PA + improved ($p < .05$); UC worsened ($p < .05$) **Apathy:** AES, PA+ improved ($p < .05$); NS UC **QOL:** QOL-AD (total and patient), PA + improved ($p < .05$); UC worsened ($p < .05$) **QOL:** CBS, PA + improved ($p < .05$); NS UC

Table 3. Continued

Study	Participants	Caregiver interventions	Caregiver measures and outcomes	Care recipient interventions	Care recipient measures and outcomes
Marques et al. (2015) Mixed Methods w/a Single Arm Feasibility Trial B/L, post (12 weeks) *N* dyads = 9	**CG:** Family members; *N* = 9 (8F/ 1M); age = 63.8 years **CR with COPD:** COPD, *N* = 35 (2F/7M); age = 69.6 years Demographics provided only on the portion of participants involved in the feasibility trial.	**CG intervention:** Primary care clinic Psychosoc ± Educ: psychosocial support and education for CG and CR together; 12 weeks/1×/week/90 min	**Family coping:** F-COPES, improved in passive appraisal (p = .043), and total score (p = .011); NS in social support, reframing, spiritual support, and accepting help **Adjustment to illness:** PAIS-SR, improved in sexual relationship (p = .013), and psychological distress (p = .012); NS in health care orientation, domestic environment, extended family relationships, social environment, and total score All comparisons *t*-tests.	**CR intervention:** Primary care clinic Rehab ± Psychosoc ± Educ: Pulmonary rehabilitation (endurance, resistance, balance), 12 weeks/3×/week/60 min; plus psychosocial support and education for CR and CG together, 12 weeks/1×/week/90 min	**Dyspnea:** mMRC, NS **Quadriceps strength:** 10RM, increased strength (p = .002) **Walking distance:** 6MWD, increased by 26.8 m (p = .023) **Mobility and balance:** TUG, improved (p = .002) **Health-related QOL:** SGRQ, NS **Family coping:** F-COPES, improved in social support (p = .018), accepting help (p = .027), passive appraisal (p = .043), and total score (p = .026); NS in reframing and spiritual support. **Adjustment to illness:** PAIS-SR, NS in all subscales and total All comparisons *t*-tests.
Yu et al. (2015) Pilot, Feasibility Study w/a Single. Arm B/L, post (3 months), F/U (6 months) *N* dyads = 26	**CG:** Family members; *N* = 26 (20F/6M); age = 64 years **CR with Alzheimer's Disease:** *N* = 26 (16F/10M) community-dwelling, age = 78 years	**CG intervention:** Respite CGs received 8–10 hr/week; researchers transported CRs to and from gym setting	**Distress:** NPI-Q, B/L to 3 months: NS, though an 8% decrease 3 to 6 months: Decrease of 32% ($p < .05$) **CR behavior:** NPI-Q, 3 and 6 months: NS, but maintained B/L score All comparisons MEtime.	**CR interventions:** Community Cycling: Moderate intensity cycling, supervised, individualized, 6 months/3×/week/15–45 min, plus 10 min each of warm-up and cool down	**Cognition:** ADAS, 3 and 6 months: NS, but maintained B/L score **ADLs:** DAD 3 and 6 months: NS, but maintained B/L score All comparisons MEtime.

Key - General Abbreviations: ADLs = activities of daily living; B/L = baseline; CG = caregiver; CR = care recipient; F/U = follow up; PA = physical activity; Rx = prescription; UC = usual care (also treatment as usual).

Key - Measures Abbreviations: 6MWD = 6-meter walking distance; 10RM = 10-repetition maximum; ADAS = Alzheimer's Disease Assessment Scale; ADCS-ADL = Alzheimer's Disease Cooperative Study—Activities of Daily Living; AES = Apathy Evaluation Scale; BADL = Bristol Activity of Daily Living Index; BDI = Beck Depression Inventory; CBI = Caregiver Burden Inventory; CBS = Cornell-Brown Scale for Quality of Life in Dementia; CSDD = Cornell Scale for Depression in Dementia; DAD = Disability Assessment for Dementia; EQ-5D = EuroQOL-5 dimension; FAB = Frontal Assessment Battery; F-COPES = Family-Crisis Oriented Personal Scale; HAM = Hamilton Anxiety Rating Scale; mMRC = Modified Medical Research Council Dyspnea Scale; MMSE = Mini-Mental State Exam; NPI-Q = Neuropsychiatric Inventory Questionnaire; PAIS-SR = Psychosocial Adjustment to Illness Scale-Self-Report; PPB = Physical Performance Battery; QOLAD = Quality of Life Scale in Alzheimer's Disease; SFT = Senior Fitness Test; SGRQ = St. George's Respiratory Questionnaire; TUG = Timed Up and Go test; ZBI = Zarit Burden Interview.

Key - Statistical Tests Abbreviations: BtwGrp = between groups; ES = effect size; MEtime = main effect of time; SD = standard deviation; w/iGrp = within group.

Results

Study Selection

The database search yielded 9,684 articles, of which 4,733 articles were duplicates, which occurred due to the replication of studies catalogued across all searched databases. An additional 22 articles were identified based upon published protocol and method papers found in the original database search. After the removal of duplicates, reviewers screened the remaining 4,951 titles. Using the research question and inclusion criteria to determine selection, title screening yielded 1,093 abstracts meeting the established criteria (Figure 2). Following abstract screening, 107 articles remained and went through full-text review. Of the full-text articles, 96 did not meet the inclusion criteria, and thus were excluded for the reasons noted in Figure 2 (e.g., studies lacked a clear definition of the caregiver; exercise was not the primary focus of the study, etc.). Eleven articles met inclusion criteria. All final articles were cross-referenced within Retraction Watch, and researched in PubMed and Google Scholar on January 17, 2019 with no retractions issued for any included articles.

Study Characteristics

Final studies included five RCTs (Badger, Segrin, Dorros, Meek, & Lopez, 2007; Lamb et al., 2018; Lowery et al., 2014; Maci et al., 2012; Winters-Stone et al., 2016), and six nonRCTs (Barnes et al., 2015; Burgener, Marsh-Yant, & Nega, 2011; Canonici et al., 2012; Marques et al., 2015; Milbury et al., 2015, 2018; Yu et al., 2015). Study designs and characteristics can be found in Tables 2 and 3. Sample sizes ranged from 5 to 459 participants. To best interpret the results, studies were grouped into two categories: (a) caregiver–care recipient dyads exercised together (DyEx; *N* = 6; Table 2) and (b) caregiver–care recipient dyads were enrolled, but only care recipients exercised while caregivers received a separate, nonexercise intervention or UC (DySplit; *N* = 5; Table 3).

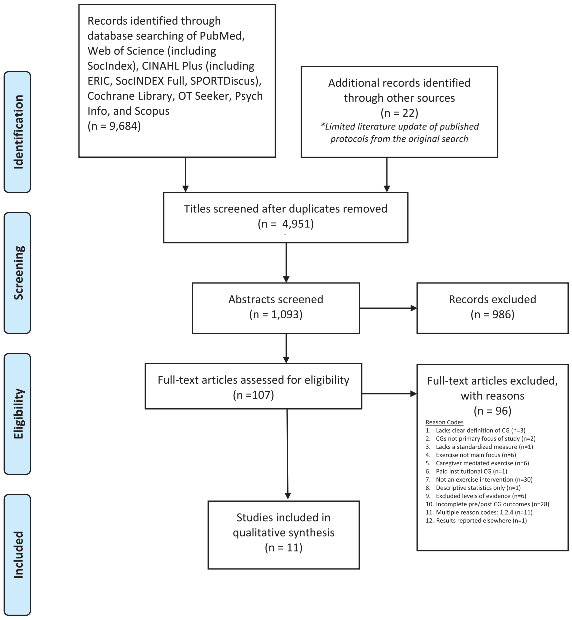

Figure 2. PRISMA flow chart of study selection.

Participants

Overall, studies enrolled 862 family caregivers (DyEx = 343, DySplit = 518) with a mean age of 67.1 years (DyEx = 66.1 years, DySplit = 70.5 years), and 69.4% were female caregivers (DyEx = 63.2%, DySplit = 75.3%). DyEx had a higher percentage of male caregivers due to one study of 96 dyads conducted for females with breast cancer and male spouses (Badger et al., 2007). Across studies, spouses comprised 68.1% of caregivers (DyEx = 58.9%, DySplit = 70.5%); 29.4% were adult children (DyEx = 39.4%, DySplit = 26.4%).

Care recipients were older adults with Alzheimer's disease or dementia (DyEx = 2, DySplit = 4), cancer (DyEx = 4), and chronic obstructive pulmonary disease (DySplit = 1). The 865 care recipients (DyEx = 311, DySplit = 554) were a mean age of 72.3 years (DyEx = 66.9 years, DySplit = 76.9 years); 46.9% were female (DyEx = 57.2%, DySplit = 40.7%), and 53.1% male (DyEx = 42.8%, DySplit = 58.8%). One study reported demographics for care recipients elsewhere (Burgener et al., 2011).

Interventions and Comparison Groups

Interventions and exercise prescriptions in DyEx and DySplit varied in length from 5 weeks to 6 months, 2–5 days per week for 45 min to 1.5 hr per session. Across the included studies, exercise protocols varied in intensity. Five studies prescribed the exercises as low intensity or low impact (Badger et al., 2007; Barnes et al., 2015; Burgener et al., 2011; Milbury et al., 2015, 2018), but none provided a specific definition based on exercise physiology measures. Of the studies employing moderate- to high-intensity protocols for aerobic exercise, measures varied and included the use of a perceived exertion rating of 12–14 (Lowery et al., 2014; Yu et al., 2015), 55% VO_{2max} (Maci et al., 2012), 65%–75% heart rate reserve (Yu et al., 2015), and 60%–80% of a 6-min walk test (6MWT) at baseline assessment (Marques et al., 2015). One study used a more general definition and noted that the moderate to high-intensity aerobic and strength training components were based on participants' tolerance, in combination with baseline performance of the 6MWT (Lamb et al., 2018). Studies using more specific measures of resistance training protocols noted an 8–15 repetition maximum (RM) for upper body, an 8–15 RM at 4%–15% of body weight for lower body (Winters-Stone et al., 2016), and 50%–85% of the 1RM for upper and lower body (Marques et al., 2015).

DyEx interventions included self-managed walking programs (Badger et al., 2007; Lowery et al., 2014), yoga (Milbury et al., 2015, 2018), strength training (Winters-Stone et al., 2016), and taiji (Burgener et al., 2011). In three studies, dyads engaged in some exercises as a co-occupation (Milbury et al., 2015, 2018; Winters-Stone et al., 2016), such that they entailed interactive and interdependent participation as a couple. The other three studies entailed the dyads performing the same exercises, but did not require coordinated interaction (Badger et al., 2007; Burgener et al., 2011; Lowery et al., 2014). Of the DyEx interventions, four utilized comparison cohorts (Badger et al., 2007; Burgener et al., 2011; Lowery et al., 2014; Winters-Stone et al., 2016). One study, Badger et al. (2007), compared exercise to telephone counseling and an attention control. The other three studies employed UC cohorts (Burgener et al., 2011; Lowery et al., 2014; Winters-Stone et al., 2016); however, none defined what UC entailed. Burgener and colleagues (2011) offered bimonthly educational programs in conjunction with UC to control for the attention given to the treatment cohort and Winters-Stone and colleagues (2016) noted that UC participants were also directed to maintain their typical physical activities. The remaining two DyEx studies (Milbury et al., 2015, 2018) did not utilize a comparison group.

Four DySplit studies employed mixed modalities of exercise for care recipients (Barnes et al., 2015; Lamb et al., 2018; Maci et al., 2012; Marques et al., 2015); the fifth study involved cycling (Yu et al., 2015). In all five studies, care recipients exercised, while caregivers received separate, nonexercise interventions or UC. Three DySplit studies provided a separate intervention to caregivers (Marques et al., 2015; Maci et al., 2012; Yu et al., 2015). Of the studies providing a separate intervention, one study targeted both members of the dyad to receive psychosocial support and education together once weekly for 90 min over 12 weeks (Marques et al., 2015). The two other DySplit studies that offered a separate intervention for caregivers arranged for them to receive 8–20 hr per week of respite by transporting care recipients to and from intervention settings (Maci et al., 2012; Yu et al., 2015). Caregivers received UC in two studies (Barnes et al., 2015; Lamb et al., 2018). The study by Barnes and colleagues (2015) also utilized a UC cohort, which was undefined for the caregiver, but was supplemented with four in-home visits and biweekly calls to the dyad; however, the emphasis was on the care recipient's exercise, goals, and adverse events (Barnes et al., 2015). For care recipients in Barnes and colleagues (2015), the UC cohort continued with seated exercises and activities typical of an adult day care. In Lamb and colleagues (2018), the UC-only cohort received the typical clinical guidance offered to caregiver–care recipient dyads.

Outcomes

Caregiver Psychosocial Well-Being

All studies (N = 11) examined psychosocial well-being of caregivers with emphasis on mental health (depression, anxiety, distress, stress), quality of life (burden, fatigue, sleep, and general QOL), relationships (couple, family, social, spiritual), and perceptions of care recipients (symptoms, behavior, QOL). Results were mixed across and within DyEx and DySplit studies.

Of the DyEx studies, six examined caregiver psychosocial well-being. Beneficial outcomes in four studies indicated significant improvements in mental health (Badger et al., 2007; Canonici et al., 2012), QOL (Burgener et al., 2011; Canonici et al., 2012; Lowery et al., 2014), relationship quality (Burgener et al., 2011), and perceptions of the care recipients' symptoms (Milbury et al., 2018). Though nonsignificant, two studies reported trends or moderate effect sizes suggesting enhancements to some aspects of mental health (Burgener et al., 2011; Milbury et al., 2018). However, no significant findings were reported for other mental health indicators (Burgener et al., 2011; Lowery et al., 2014; Milbury et al., 2015; Winters-Stone et al., 2016), QOL (Milbury et al., 2015, 2018), relationships (Milbury et al., 2015), or perceptions of care recipients (Lowery et al., 2014). One small pilot study of five dyads doing yoga reported significant worsening of depression with a large effect size (Milbury et al., 2018); researchers surmised the results may have been due to the intervention's secondary focus on mindfulness, which could have resulted in caregivers accepting the poor prognosis for their loved ones.

In three DySplit interventions, caregivers experienced significant improvements to mental health when they were offered nonexercise interventions of either respite (Maci et al., 2012; Yu et al., 2015) or a dyadic support group (Marques et al., 2015), while their care recipients exercised. The support group intervention also saw significant relationship benefits (Marques et al., 2015). Two studies that provided UC did not realize any significant changes to caregiver mental health or QOL (Barnes et al., 2015; Lamb et al., 2018). Three studies examined caregivers' perceptions of care recipients' health, but results were mixed such that one study reported improvements (Maci et al., 2012), while two others saw no significant differences (Barnes et al., 2015; Yu et al., 2015).

Caregiver Physical Well-Being

Three DyEx studies measured caregiver physical health. A resistance training intervention noted significant increases in muscle mass, strength, and physical function, but no significant difference in gait speed (Winters-Stone et al., 2016). Self-reported physical outcomes were equivocal. One study demonstrated significant increases in physical health and activity (Winters-Stone et al., 2016), whereas two yoga studies conducted by the same researchers reported nonsignificant, oppositional findings in physical well-being—one indicating improvements (Milbury et al., 2015), the other showing decrements (Milbury et al., 2018). In their later study, Milbury and colleagues (2018) did not specifically address why caregivers' physical well-being may have decreased; however, researchers did note the lack of a control group and small sample size were limitations to ascertaining the strength of results. No DySplit interventions examined physical well-being in caregivers.

Care Recipient Outcomes

Given the review's emphasis on caregivers, outcomes for care recipients are reported in Tables 2 and 3. To synthesize, authors reported mixed findings with some beneficial effects for care recipients in varying indicators of psychosocial, physical, and functional well-being across both DyEx and DySplit studies.

Quality Assessment and Risk of Bias

The modified Downs and Black quality assessment scores ranged from 13 to 22 points (mean = 17) out of 27 possible (Table 4). Three met criteria for good methodological quality, seven fair, and one poor. Of the three rated as good quality, two were DyEx studies (Lowery et al., 2014; Winters-Stone et al., 2016), and one DySplit study (Lamb et al., 2018); all three were medium to large-scale RCTs scoring higher for reporting and internal validity, with adequate power and analyses. Due to the nature of the interventions, no included RCTs blinded study subjects; no study met the criteria for external validity.

Discussion

This systematic review examined whether caregivers, who enroll with their care recipients in dyadic exercise interventions, realize greater health benefits when they coparticipate in exercise, or when their care recipients exercise independently while the caregivers receive another nonexercise treatment or UC. Results of this review are limited by the number and quality of studies that have specifically addressed and included caregivers as the primary focus of the study, and by the varied assessment techniques used for each study.

Although some results were mixed and outcome measures varied across studies, our findings indicate that when exercising together with care recipients, caregivers were more likely to experience improvements in both psychosocial and physical health. In comparison, caregivers who did not exercise, but did receive a separate, nonexercise intervention—specifically planned respite or a dyadic support group—were only measured for psychosocial outcomes, and thus more likely to show psychosocial benefits. Those caregivers who received UC were less likely to derive either physical or psychosocial health benefits. In both DyEx and DySplit studies, care recipients also improved in physical

Table 4. Quality and Risk of Bias Assessment Using the Modified Downs and Black Checklist

	DyEx studies (*n* = 6)						DySplit studies (*n* = 5)				
	Badger et al. (2007)	Burgener et al. (2011)	Lowery et al. (2014)	Milbury et al. (2015)	Milbury et al. (2018)	Winters-Stone et al. (2016)	Barnes et al. (2015)	Lamb et al. (2018)	Maci et al. (2012)	Marques et al. (2015)	Yu et al. (2015)
Reporting	10	8	10	0	11	11	9	11	7	9	8
External Validity	0	0	0	0	0	0	0	0	0	0	0
Internal Validity—Bias	5	6	5	3	4	6	5	6	6	4	6
Internal Validity—Confounding	1	1	5	2	2	4	3	4	3	0	2
Power	0	0	1	0	0	1	0	1	0	0	0
Total Score and	16	15	21	15	17	22	17	22	16	13	16
Quality Rating	Fair	Fair	Good	Fair	Fair	Good	Fair	Good	Fair	Poor	Fair

Note: Quality rating: Excellent (26–28), Good (20–25), Fair (15–19), Poor (≤14).

and psychosocial outcomes following exercise, although outcome measures were heterogeneous and results were mixed. Most studies were of low to moderate quality and moderate to high risk of bias. Results suggest that spousal and family caregivers may gain more from engaging in dyadic exercise compared to when their care recipients exercise independently.

The bulk of research focuses on interventions for individuals with a given pathology, but addresses caregivers only secondarily, if at all. The critical problem this introduces is a cadre of studies that have not been well designed to address outcomes for caregivers. Randomization has occurred based on the care recipient, selected outcome measures are inconsistent, and often caregiver demographics are not considered as part of the study. Although it is certainly understandable why researchers have elected to focus the effects of an intervention on individuals with pathologies, the current approaches often count, as ancillary, a key member of the team that determines the effectiveness of an intervention.

Moreover, the studies included in this review encompass only a small segment of pathologies experienced by caregiver–care recipient dyads, namely those with Alzheimer's disease, cancer, dementia, and chronic obstructive pulmonary disease. Undoubtedly, the caregiving requirements and burdens vary—not only for the ones covered in the present review, but also for many other pathologies affecting older adults. Unfortunately, studies excluded from the present review covered additional pathologies, such as cardiovascular disease, diabetes, osteoarthritis, Parkinson disease, and stroke (see Supplementary Table 1 for a list of excluded full-text articles). Though the titles and abstracts of these studies mentioned caregivers, the study designs did not fully address caregiver outcomes. Lastly, the heterogeneous nature of the interventions, which included cycling, strength training, taiji, walking, yoga, and mixed modes of exercise—all with varying outcomes for caregivers and care recipients—makes it difficult to advocate for one form of PA over another. Given these considerations, results of the present review should be interpreted with caution.

Support for Exercising Together as a Dyad

A growing body of literature supports the use of dyadic psychosocial and behavioral interventions as a means for addressing the negative outcomes experienced by couples living with various chronic illnesses (Martire et al., 2010). The present review aligns with the meta-analysis of 33 educational and behavioral interventions for couples conducted by Martire and colleagues (2010), which reported small, but significant effects on psychosocial outcomes for care recipients, and when measured, caregivers. However, many of the studies placed an emphasis on care recipients and offered limited insights on the effects of such interventions for caregivers. Moreover, Martire and colleagues (2010) included just three exercise studies, of which only one assessed outcomes in both caregivers and care recipients, and is included in the present review (Badger et al., 2007). The other two exercise studies paired couple-oriented behavioral therapy with patient-only exercise for older adults with osteoarthritis (Keefe et al., 2004) and low back pain (Turner, Clancy, McQuade, & Cardenas, 1990).

The present review expands the evidence available to support dyadic exercise interventions, and in particular, to lend support to the efficacy of such interventions for caregivers when they coparticipate in the exercise and are assessed for outcomes. In our review, five DyEx studies reported significance or trends for improvement in caregiver psychosocial health, and two DyEx studies reported significant enhancements to physical and functional outcomes for caregivers. Similar to our findings, a recent review of four dyadic exercise interventions supported some favorable health outcomes for dementia caregivers with two studies showing decreased burden (Lamotte, Shah, Lazarov, & Corcos, 2016). However, Lamotte and colleagues (2016) noted mood states were inconsistent such that one small controlled trial described improvements (Canonici et al., 2012); whereas two larger RCTs reported no significant differences (Lowery et al., 2014; Prick, de Lange, Twisk, & Pot, 2015). Of the four studies comprising Lamotte and colleagues (2016), three were excluded from the present systematic review due to a lack of pre- and post-test outcomes for caregivers (Pitkala et al., 2013), an emphasis on caregivers assisting with the exercises (Prick et al., 2015), and in the third study, it was ambiguous as to whether caregivers were co participating or receiving separate treatment (Canonici et al., 2012).

Interestingly, results of DyEx studies are also similar to outcomes reported in a review of PA interventions tailored to caregivers, such that caregivers are the focus, and the only ones to exercise (not to be confused with DySplit studies, in which the care recipient exercised independently and the caregiver received a separate, nonexercise intervention or UC). Similar to DyEx interventions, caregiver-only exercise studies, targeted to family caregivers of adults living with a wide range of chronic illnesses, primarily emphasized psychosocial health yielding mixed results with significant improvements and varying efficacy in selected outcomes (Lambert et al., 2016; Loi et al., 2014; Orgeta & Miranda-Castillo, 2014). Findings for physical health were also equivocal. Lambert and colleagues (2016) concluded caregiver-only interventions increased physical activity levels, and improved blood pressure, but only half of the reviewed studies found a positive impact on other physical health indicators (Lambert et al., 2016).

Given the semblance of results between dyadic and caregiver-only exercise, it then becomes relevant to consider whether caregivers benefit more from dyadic exercise or from caregiver-only exercise. It is not surprising that caregivers attained benefits from participating in exercise, whether the intervention involved the dyad or caregivers only, because the literature supports the role of physical activity in the healthy aging of older adults (Bauman et al., 2016). However, among barriers to caregiver-only exercise interventions are perceptions of increased burden (Hirano et al., 2011b), inability to leave care recipients, and few opportunites to partake in physical activities with them (Janevic & Connell, 2004; Malthouse & Fox, 2014). These barriers pose limitations to caregiver-only exercise studies, making it difficult to translate and maintain them (Cuthbert, King-Shier, Ruether, Tapp, & Culos-Reed, 2017), and as such may suggest a possible advantage of dyadic exercise interventions.

Further supporting dyadic interventions, Burgener and colleagues (2011) postulated that dementia caregivers gained feelings of empowerment and improved the quality of their relationships because they coparticipated in interventions to enhance care recipients' well-being. Also relevant, Badger and colleagues (2007) cited mutual spousal influences on health as a reason for reciprocal decreases in depression and anxiety for women with breast cancer and their spouses. Dyadic exercise may also prove helpful in overcoming caregivers' diminished social interaction as a barrier to physical activity. For example, Lowery and colleagues (2014) noted dyadic walking afforded dementia caregivers an opportunity to receive and provide psychosocial support, which may have been enough to precipitate decreases in their burden, despite no change in care recipients' behavioral symptoms (Lowery et al., 2014). Further, Winters-Stone and colleagues (2016) attributed improvements to physical and mental health seen in cancer dyads to the emphasis on co-occupational exercises that encouraged interdependent and interactive participation as a couple (Winters-Stone et al., 2016).

Dyadic interventions may offer many advantages to spousal caregivers and care recipients when both exercise. However, previous work is limited in scope and methodology, which is further discussed subsequently. Recently, though, a study published outside the timeframe of this review, implemented a large community-based intervention combining multicomponent exercise with behavioral treatment for dementia dyads; both members of the dyad increased the days they engaged in physical activity together, and caregivers improved in depression, but not physical measures of health (Teri, Logsdon, McCurry, Pike, & McGough, 2018). In general, more work is needed to understand the efficacy and applicability to a broader spectrum of caregiver–care recipient dyads.

If Not Exercising, Respite or a Separate Intervention

For researchers interested in focusing the exercise on the care recipient, the present review suggests it may be advantageous to provide a separate intervention for caregivers. Three pilot DySplit studies in the present review were identified as specifically enrolling a dyad, and providing respite or a separate, nonexercise activity for the caregivers, while their care recipients exercised. These three pilot studies reported psychosocial benefits for caregivers; however, none measured physical health. In contrast, caregivers only receiving UC did not observe significant psychosocial benefits, and neither measured physical outcomes.

Corroborating findings of the present review, two systematic reviews examining various forms of respite and caregiver support indicated positive, but small to moderate effects on psychosocial outcomes for family caregivers of frail elderly individuals (Lopez-Hartmann, Wens, Verhoeven, & Remmen, 2012; Shaw et al., 2009). A qualitative study noted that an often-overlooked need for older adult caregivers is respite, which provides temporary relief from their responsibilities (Johnson, Hofacker, Boyken, & Eisenstein, 2016). Caregivers indicated a strong interest in interventions that specifically designate respite and access to support groups (Johnson et al., 2016).

Planned respite or a caregiver-specific portion of the intervention may be more advantageous to caregivers than simply not engaging in an exercise program. Certainly, one could argue that caregivers receive respite when care recipients are solely engaged in exercise interventions, whether that respite is planned or not. However, caregivers are often the ones who must help prepare and transport care recipients to and from the interventions. As such, this may add to their typical caregiving workload, and put additional onus on them to ensure care recipients' participation and adherence, which detracts from the value of respite (Shaw et al., 2009).

In the review by Shaw and colleagues (2009) of respite effects on caregivers of older adults, the authors recommended respite be made available in a range of services, and that it be flexible and responsive to caregivers' and care recipients' needs. Two studies in the present dyadic exercise review provided planned respite for caregivers by transporting dementia care recipients to and from the intervention sites. Combined duration of the transportation and the intervention gave caregivers between 8 and 10 hr (Yu et al., 2015) and up to 20 hr (Maci et al., 2012) per week of respite. Maci and colleagues (2012) reported that caregivers significantly improved in mood and perception of care recipients' quality of life. Similarly, caregivers in Yu and colleagues (2015) experienced a 40% decrease in burden, which they attributed to both the respite and improvements made by their care recipients, and facilitated easier caregiving. In the study by Marques and colleagues (2015), caregivers of individuals with chronic obstructive pulmonary disease improved in family coping strategies and psychosocial adjustment, which they ascribed to the dyadic support group helping them cope with the illness as a team, thus enhancing their relationships with care recipients.

As with exercise interventions targeting the dyad, there may be many advantages to spousal and family caregivers when they are offered planned respite or a simultaneously occurring intervention while their care recipients exercise.

Again, though, the small number of studies reviewed herein limit generalizations, but merit further investigation that places greater emphasis on designing studies specifically with caregivers in mind.

Limitations of the Included and Excluded Studies

Most of the included studies were scored as fair to good quality and moderate to high risk of bias. These findings can be largely attributed to the fact that caregivers were not the focus of the study but rather a tangential sample to the individuals being studied. Nearly half of the excluded studies were removed based upon how caregiver data were handled. For example, multiple studies were eliminated during the full-text review for failing to provide pre- and post-test outcomes for caregivers; lacking a precise and congruent description of caregivers and their role in the exercise program; and placing an emphasis on caregivers assisting with the exercises, and thus lacking a control for or report on how much all caregivers were actually able to engage in the exercise themselves. See Supplementary Table 1 for a list of excluded full-text articles.

Given the number of studies that mentioned or included the caregiver in the abstract, it is apparent researchers are interested in investigating how exercise impacts caregivers. As the field moves forward, it is important to correct the shortcomings and specifically design interventions around both members of the dyad. This is especially valid given the body of literature that demonstrates the reciprocal influence spouses can have on each other's mental and physical health, as well as exercise behaviors.

Limitations of the Review

This review is limited in that it cannot be generalized to all caregiver–care recipient dyads. Inclusion criteria required studies to clearly define caregivers and provide baseline demographics along with pre- and post-test outcomes. Additionally, care recipients in the included studies were predominantly diagnosed with cancer and dementia; thus, caregiving demands associated with other chronic conditions may differentially influence results. Moreover, the methodological quality of the studies, combined with heterogeneity of the exercise interventions, outcome measures, and statistical analyses, prevent a meta-analysis of the data, as well as a comparison of intervention efficacy, thus allowing only general conclusions about dyadic exercise and its impact on caregivers. Also, the broad definition used to identify dyadic exercise interventions was constructed to suit the scope of this review, and therefore may not necessarily reflect the intentions of the researchers. Finally, the search included only quantitative studies published in English, thereby overlooking qualitative results, as well as reports in other languages.

Implications

The present systematic review extends the knowledge of dyadic exercise interventions involving caregivers of older adults, and encompassed a cross-disease examination of primarily caregiver outcomes, but also effects on care recipients. Employing a broad definition of the dyad allowed us to compare caregiver outcomes in two different variations of dyadic interventions, namely those in which both members of the dyad exercised, and those in which only care recipients exercised, while caregivers received a separate nonexercise intervention or UC. This enabled a comparison with the goal of identifying what yields the best results for caregivers. PRISMA reporting guidelines were followed to enhance the quality and replication of the results. To address publication bias and provide the most current information available, we conducted a limited literature update of previously published protocols found during our title and abstract review.

Exercise has the potential to improve health in both members of a caregiver–care recipient dyad. Yet caregivers are often overlooked for participation, and examined only secondarily in exercise interventions for care recipients. This analysis suggests caregivers may benefit both physically and psychosocially from dyadic exercise interventions that intentionally involve their coparticipation. Interventions that offer a separate, nonexercise cohort or planned respite may also benefit caregivers' mental health, and in the case of planned respite may empower them to self-select how they use their time. However, the mixed benefits of both types of dyadic interventions suggest that the exercise formats and/or the type of respite program offered, as well as the pathologies of care recipients, and the related caregiving demands are all important variables to consider when measuring caregiver outcomes. To foster the uptake and translation of these interventions, future research for caregivers should include larger-scale randomized control trials, more rigorous methodologies that intentionally plan for the caregiver, other populations of older adult caregivers across a broader spectrum of diseases, and comparative investigations of dyadic exercise versus caregiver-only and care recipient-only exercise, as well as respite options. Equally important, if not more so, is taking the time to understand the interests and needs of the caregivers through mixed-method approaches including qualitative assessments to interview and survey caregivers to inform intervention design, dosage, and implementation.

Moreover, from a public health perspective, bolstering the physical and psychosocial well-being of caregivers, through physical activity, will help contain the escalating costs associated with elder care and institutionalization in the United States, which are estimated to range between \$470 billion (Reinhard, Feinberg, & Houser, 2015) and \$522 billion (Chari, Enberg, Ray, & Mehrotra, 2015). It is important to make advances toward policies, strategies, research funding, and public discourse that supports and promotes community-based and in-home health promotion and wellness programs to encourage physical activity for dyads of older adult caregivers and care recipients. Also necessary are policies that support working family caregivers, such as adult children. More family and medical leave, paid family leave, and financial assistance or incentives to participate in physical activities and other interventions may improve caregiver health and well-being, but also the well-being of their care recipients to help them age in place and avoid institutionalization.

Supplementary Material

Supplementary data are available at *The Gerontologist* online.

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Conflict of Interest

None reported.

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COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	38
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	38-39
Occupation	3	What was their occupation at the time of the study?	38-39
Gender	4	Was the researcher male or female?	38-39
Experience and training	5	What experience or training did the researcher have?	38-39
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	39
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	39
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	39
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	33 and 36
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	34
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	34 and 35
Sample size	12	How many participants were in the study?	34
Non-participation	13	How many people refused to participate or dropped out? Reasons?	47, 83-84
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	38
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	38
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	36, 48
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	36-37
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	33, 38
Field notes	20	Were field notes made during and/or after the inter view or focus group?	38
Duration	21	What was the duration of the inter views or focus group?	38
Data saturation	22	Was data saturation discussed?	40, 49
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	39, 40
Description of the coding tree	25	Did authors provide a description of the coding tree?	39-40
Derivation of themes	26	Were themes identified in advance or derived from the data?	37, 39-40
Software	27	What software, if applicable, was used to manage the data?	39-40
Participant checking	28	Did participants provide feedback on the findings?	n/a
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	48-92
Data and findings consistent	30	Was there consistency between the data presented and the findings?	85-95
Clarity of major themes	31	Were major themes clearly presented in the findings?	48-92
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	48-92

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Appendix CC

Phone Script for Recruitment, Pre-Screening and Enrollment

Identifier #_____________

PC1 date/time & result _____/______/____

PC2 date/time & result _____/______/____

PC3 date/time & result _____/______/____

PC4 date/time & result _____/______/____

PC5 date/time & result _____/______/____

Phone script will be used in 4 scenarios:

1) Potential participant calls researcher after reading e-mail, web, flyer, poster or seeing Facebook post.

2) Potential participant contacts researcher by email and provides contact phone number.

3) Someone else answers the phone, and indicates that the person(s) are not available.

4) If the call is answered by an answering machine or voicemail.

1. Phone Script for Recruitment

Scenario #1- Potential participant *calls* researcher

Researcher: Hi. This is ____.

Participant: Hi. I'm calling about the Parkinson disease study for couples and care partners.

Researcher: Thanks for calling me. I am one of the researchers for the study. I need to tell you and your spouse/partner or family member a few things about the research and ask both of you some questions to see if you are eligible to participate. It will take about 5-10 minutes. Is this a good time to talk?

_____ If YES – continue with script – go to p.3.

_____ If NO – When will be a good time for me to call you back? Time/day: ______________

What number should I call? ________________________

Scenario #2- Potential participant leaves message/e-mail and is *contacted by* researcher

Researcher: Hello, my name is ____, and I am calling from the Sensory Motor Integration Lab at UW-Madison. I am calling to speak with ____ [name(s) of individual(s) who contacted us]. [If someone else answers and indicates that the person(s) listed above are not available, skip to #3 below; or skip to #4 if answering machine/voice mail.] You contacted us about a Parkinson disease study for couples and care partners. I am one of the researchers for the study. I need to tell you and your spouse/partner/family member a few things about the research and ask both of you some questions to see if you are eligible to participate. It will take about 5 minutes. Is this a good time to talk?

_____ If YES – continue with script – go to p.3.

_____ If NO – When will be a good time for me to call you back? Time/day: ______________

Should I call you at this number? Yes/no/alternate number_______________________

Scenario #3- Someone else answers the phone, and interested person is not available.

Researcher: Hello, my name is ____, and I am calling from the Sensory Motor Integration Lab at UW-Madison. When _______________________ [name of individual(s) who contacted us] is available, please ask them to call us at (608) 262-2712 regarding participation in a research study. Thank you!"

**** DO NOT PROVIDE ANY FURTHER STUDY DETAILS ****

Scenario #4 – Answering machine or voice mail answers the call.

Researcher: Hello, my name is ____, and I am calling from the Sensory Motor Integration Lab at UW-Madison. I am calling to follow-up with ___________________ [name of individual(s) who contacted us] regarding participation in a research study. Please give us a call back at a time that is convenient for you. Our phone number is (608) 262-2712. We look forward to talking with you. Again our number is (608) 262-2712. Thank you!"

**** DO NOT PROVIDE ANY FURTHER STUDY DETAILS ****

2. Description of Study: Review this study description.

Note to researcher: *Prior to beginning the phone screening process, verbal consent must be given by the individual(s). Please read the script below and only proceed with the phone screen procedure, if consent has been provided.*

I am calling to follow-up with you because you expressed interest in our study about **exploring in-home exercise for spouses and care partners living with Parkinson disease**. This study is being conducted by Dr. Kristen Pickett, Kecia Doyle, and other members of Dr. Pickett's research team at UW-Madison. The purpose of this research study is to investigate possible options for developing a dyadic or couples version of an in-home exercise intervention for individuals with Parkinson disease and their spouses or care partners living in underserved communities.

This research will study your experiences with Parkinson disease for both members of the dyad, your attitudes and barriers to exercise, along with your interests in participating in home-based exercise. Your answers will help us explore the possible development of an in-home exercise intervention delivered via telehealth for PD couples/care partners, and what needs you might have in order to participate. The study involves two key activities: 1) participating in a telephone or web-based interview—one with each member of the dyad/pair—that will take about 1 ½ to 2 hours; and 2) completing and returning some questionnaires about your activities of daily living, balance and falls confidence, current participation in exercise, your relationship with each other, as well as some demographics and health history information. For this study, no in-person visits to the university or to your home will take place. All data collection will be completed via phone or web-based conferencing, and mail-in forms.

If you decide that you are interested in participating in our study, we will take each of you through an initial list of questions over the phone to determine your eligibility for the study. This can be done today or at a later date if that is more convenient. Participation in any part of this phone call as well as in the research study is voluntary. You may withdraw, or stop participating, at any time. If one member of your dyad/couple opts out of the study, the other member of the dyad/couple may choose to continue participating or opt out, as well.

Do you have any questions about the study?

Are you interested in completing that initial set of questions with me over the phone now to see if you meet the study qualifications?

_____**If YES,** proceed to page 4 for the caregiver/partner screening, or p.5 for the individual with PD.

_____ **If NO,** see if they would like to schedule a later call. If not, say "Thank you for talking with me today and for your interest in our study. We will remove you from our call list at this time, but we do appreciate your consideration of this work."

3. Phone Screening – Caregiver/Care Partner

(Use this form to assess a caregiver/care partner's eligibility for the study. If the participant is not eligible for participation, their screening information will be destroyed.)

The following questions are being asked to determine if you and your spouse/partner/family member meet the eligibility requirements for our study to explore the development of an in-home exercise program for individuals with Parkinson disease and their spouses/family members or care partners. As I mentioned, answering these questions is completely voluntary -- you don't have to answer any of these questions. Your answers will be kept confidential. If one member of your dyad/couple opts out of the study, the other member of the dyad/couple may choose to continue participating or opt out, as well.

1. What is your age today? *(Must be at least 45 years old)*	______________
2. What is your relationship to the person with Parkinson disease?	Check one: ☐ Spouse ☐ Partner ☐ Adult Child ☐ Family member: *(Specify relation.)* _________________________ ☐ Other: *(Specify relationship.)* _________________________
3. Do you currently provide unpaid or paid care/assistance to the person with Parkinson disease (PD)? (*Must select unpaid care or assistance.)*	Check all that apply: ☐ Unpaid care or assistance ☐ Paid care
4. Do you speak English? *(Must answer "yes".)*	☐ Yes ☐ No
5. Do you agree to participate in the interview? *(Must select "yes".)*	☐ Yes ☐ No
6. Do you agree to complete and return all the forms? (e.g. balance and falls, exercise, health history, etc)? *(Must select "yes".)*	☐ Yes ☐ No

****CAREGIVER SCREENING CONTINUED ON THE NEXT PAGE****

7. Over the past week has your family member with PD had any problems remembering things following conversations, paying attention, thinking clearly, or finding his/her way around the house or in town?	Check Y/N and rate: ________ ☐ Yes ☐ No *(If yes, ask caregiver to elaborate and probe for information.)*

(Consider all types of altered level of cognitive function including cognitive slowing, impaired reasoning, memory loss, deficits in attention and orientation. Rate their impact on activities of daily living. MUST SELECT 0, 1, OR 2.)

☐ **0: Normal:** No cognitive impairment
☐ **1: Slight:** Impairment appreciated by caregiver with no concrete interference with the care recipient's ability to carry out normal activities and social interactions
☐ **2: Mild:** Clinically evident cognitive dysfunction, but only minimal interference with the patient's ability to carry out normal activities and social interactions.
☐ **3: Moderate:** Cognitive deficits interfere with but do not preclude the patient's ability to carry out normal activities and social interactions.
☐ **4: Severe:** Cognitive dysfunction precludes the patient's ability to carry out normal activities and social interactions.

Now, I just need to ask similar questions of your spouse/partner or family member with PD. May I speak with him/her next?

(If yes, go on to p.6. If no, schedule a time to call back (date/time): ____

7. Phone Screening – Individual with Parkinson Disease

(Use this form to assess the individual with PD's eligibility for the study. If the participant is not eligible for participation, their screening information will be destroyed.)

The following questions are being asked to determine if you meet the eligibility requirements for our study to explore the development of an in-home exercise program for individuals with Parkinson disease and their spouses/family members or care partners. As I mentioned, answering these questions is completely voluntary -- you don't have to answer any of these questions. Your answers will be kept confidential. If one member of your dyad/couple opts out of the study, the other member of the dyad/couple may choose to continue participating or opt out, as well.

1. What is your age today? *(Must be at least 45 years old)* ______________

2. Do you have Parkinson disease? *(Must answer "yes".)* ☐ Yes ☐ No

4. Do you speak English? *(Must answer "yes".)* ☐ Yes ☐ No

5. Do you agree to participate in the interview? *(Must select "yes".)* ☐ Yes ☐ No

6. Do you agree to complete and return all the forms?
(e.g. balance and falls, exercise, health history, etc)? *(Must select "yes".)* ☐ Yes ☐ No

7. Over the past week have you had any problems remembering things following conversations, paying attention, thinking clearly, or finding your way around the house or in town?
<u>Check Y/N and rate:</u> ________
☐ Yes ☐ No
(If yes, ask him/her to elaborate and probe for information.)

Consider all types of altered level of cognitive function including cognitive slowing, impaired reasoning, memory loss, deficits in attention and orientation. Rate their impact on activities of daily living. <u>MUST SELECT 0, 1, OR 2</u>.)

☐ **0: Normal:** No cognitive impairment
☐ **1: Slight:** Impairment appreciated by caregiver with no concrete interference with the care recipient's ability to carry out normal activities and social interactions
☐ **2: Mild:** Clinically evident cognitive dysfunction, but only minimal interference with the patient's ability to carry out normal activities and social interactions.
☐ **3: Moderate:** Cognitive deficits interfere with but do not preclude the patient's ability to carry out normal activities and social interactions.
☐ **4: Severe:** Cognitive dysfunction precludes the patient's ability to carry out normal activities and social interactions.

CONTINUED ON THE NEXT PAGE

If both individuals meet all inclusion criteria, go to page 8.

If one or both individuals do not meet all inclusion criteria:

Unfortunately, you and your family member have not met all of the screening requirements for the study. We are grateful for your time and interest in the study. Not meeting the criteria for this study does not mean that you are excluded from any other study being conducted in this lab or at the UW, currently or in the future. It just means that we cannot enroll you at this time. Thank you again for taking the time to talk with me.

If the individuals would like further information, refer them to Dr. Pickett (608) 890-2103.

8. Meets Basic Inclusion/Exclusion Criteria:

If both individuals meet all inclusion criteria:

Great, you have both met all screening requirements for the study. If you have 3 more minutes, I need to get your mailing address(es) so that we can send you some study materials in the mail. I will also set up two appointments to go over the project in detail, and answer all your questions. If you decide to enroll, we'll conduct the interviews, then mail you the questionnaires.

1. **Let's start with your mailing address(es):**

Spouse or Care Partner

Street: ____

____

City ________________________ State ________ Zip_______

Phone _________________________________ (best for contact)

Individual with PD ☐ Check if same as spouse/care partner

Street: ____

____

City ________________________ State ________ Zip_______

Phone _________________________________ (best for contact)

CONTINUED ON THE NEXT PAGE

2. **Now, let's look at some dates/times that work for each of you to review the study and do the interviews. We'll need about 1 ½ - 2 hours for each of you.**

   <u>Spouse or Care Partner</u>

   Date: ________________________________ Time: ________________

   <u>Individual with PD</u>

   Date: ________________________________ Time: ________________

3. **As the date of your appointment approaches, we would like to contact you by phone to remind you of your scheduled time and the location of the testing. Do you give us permission to give you a reminder call?"**

   Record response to reminder call question. □ Yes □ No

   If "Yes", date of call: ___________________________________

THANK YOU again for your time today! I'm looking forward to chatting with you during our interviews. We genuinely appreciate your interest and willingness to participate in this study.

Appendix D.1

Subject: Research Opportunity—Exploring In-home Exercise for Individuals with PD & their Care Partners

Do you and your partner or family member live with Parkinson disease (PD)? Are you interested in exploring options for exercise, but lack access to exercise programs for both of you? Would both of you be willing to share your experiences with PD and exercise, along with your interests in participating together in home-based exercise?

If so, Dr. Kristen Pickett's research team at the University of Wisconsin's Sensory Motor Integration Lab is looking for couples or family care partners to help us explore the possible development of an in-home exercise intervention delivered via telehealth for couples and care partners living with PD.

The study involves two key activities:

1) Participating in a telephone or web-based interview—one with each member of the couple or family pair—that will take about 1 ½ to 2 hours per person; and

2) Completing and returning some questionnaires about your activities of daily living, balance and falls confidence, current participation in exercise, your relationship with each other, as well as some demographics and health history information.

For this study, no in-person visits to the university or to your home will take place. All data collection will be completed via phone or web-based conferencing, and mail-in forms.

You are receiving this email because you are a member of the APDA of Wisconsin.

Each member of the couple or family pair can earn a $50 VISA gift card for participating in the study. Individuals interested in participating or those with questions about the study, please send an e-mail or call Kecia Doyle, who is a member of Dr. Pickett's research team: smil@education.wisc.edu or 608-262-2712.

Include only the following information:

"We are interested in your study exploring exercise options for dyads/couples. Please call us at ________________ (provide your telephone number) between the hours of ___ and ____ a.m. or p.m. to discuss this opportunity."

Note that e-mail is generally not a secure way to communicate sensitive or health related information as there are many ways for unauthorized users to access email. You should avoid sending sensitive, detailed personal information by email. Email should also not be used to convey information of an urgent nature.

Additionally, please feel free to share this invitation with anyone you know who may be interested! This study and the content of this email message have been approved by a University of Wisconsin-Madison Institutional Review Board (IRB). IRBs are charged with protecting the rights and welfare of people who take part in research studies.

Thank you,

The Sensory Motor Integration Lab Team (608-262-2712)

Sensory Motor Integration Lab
UNIVERSITY OF WISCONSIN–MADISON

Exploring In-Home Exercise for Individuals with Parkinson Disease & their Care Partners

- **Do you and your partner or family member live with Parkinson disease?**
- **Are you interested in exploring options for exercise, but lack access to exercise programs for both of you?**

We are looking for couples or family care partners who are willing to share your experiences with PD and exercise, along with your interests in participating together in home-based exercise. All data collection will be completed via phone or web-based conferencing, and mail-in forms.

The study involves:

1. Participating in a telephone or web-based interview—one with each member of the couple or family pair—that will take about 1 ½ to 2 hours per person; and
2. Completing and returning questionnaires.

To qualify, both participants must be 45 years of age or older, English speaking, and willing to participate in the interview, and complete and return questionnaires. One member of the care partners must be diagnosed with Parkinson disease (PD). The other individual must be a spouse, partner, adult child or family member who is providing care or assistance to the individual with PD.

For more information or for questions about the study, please send an e-mail to Kecia Doyle at smil@education.wisc.edu. Or call her at 608-262-2712.

Appendix D.3

Research Opportunity:
Exploring In-home Exercise for Individuals with PD & their Care Partners

The University of Wisconsin's Sensory Motor Integration Lab is looking for pairs of individuals with PD and their spouses, partners, or family members to help us explore the development of an in-home exercise intervention.

If you are interested in participating or have any questions about the study, please send an e-mail to Kecia Doyle at smil@education.wisc.edu. Or call 608-262-2712.

Appendix D.4

Research Opportunity:
Exploring In-home Exercise for Individuals with Parkinson Disease & their Care Partners

Do you, your spouse or family member have Parkinson disease (PD)? Are you interested in exploring options for exercise, but lack access to exercise programs for both of you? Would both of you be willing to share your experiences with PD and exercise, along with your interests in participating together in home-based exercise?

The University of Wisconsin's Sensory Motor Integration Lab is looking for pairs of individuals with PD and their spouses, partners, or family members to help us explore the possible development of an in-home exercise intervention delivered via telehealth for PD couples or family care partners.

If you are interested in participating or have any questions about the study, please send an e-mail to Kecia Doyle at smil@education.wisc.edu. Or call 608-262-2712.

University of Wisconsin-Madison
Consent to Participate in Research

Title of Study:	Exploring In-home Exercise for Individuals with Parkinson Disease & Their Care Partners
IRB Protocol #:	2020-1054
Principal Investigator:	Kristen Pickett, Ph.D. phone: (608) 890-2103 kristen.pickett@wisc.edu smil@education.wisc.edu Occupational Therapy Program Department of Kinesiology University of Wisconsin - Madison

Invitation

You are invited to participate in a research study called, "Exploring In-home Exercise for Individuals with Parkinson Disease and Their Care Partners." This study is being conducted by Dr. Kristen Pickett at the University of Wisconsin-Madison. Both of you have been asked to participate because you have expressed an interest in home-based exercise for couples or family members; and you are either an individual with Parkinson disease (PD); or you are a spouse, partner or family member providing care or assistance to the person with PD.

The purpose of this consent form is to give you the information you need to decide whether to be in the study. Ask questions about anything in this form that is not clear. If you want to talk to your family and friends before making your decision, you can. Once we have answered all your questions, you can decide if you want to be in the study. This process is called "informed consent."

Why are researchers doing this study?

The purpose of this research study is to investigate possible options for developing a couples or dyadic version of an in-home exercise intervention, delivered via a telehealth approach, for individuals with Parkinson disease (PD) and their spouses or family care partners living in underserved communities. This study is being done through the University of Wisconsin-Madison (UW-Madison). A total of about 50 people (or 25 dyads/couples) will participate in this study. No in-person visits to the university or to participants' homes or community settings will take place. All data collection will be completed via phone, web-based conferencing, and mail-in forms.

What will my participation involve?

If you decide to participate in this research you will be asked to take part in a telephone or web-based personal interview, and to complete and return some questionnaires. During the interview, two study team members will be on the telephone or web-based call. One study staff member will conduct the interview; the other staff member will take notes. We will ask you to identify and prioritize everyday issues that are important to you. We'll also ask you questions about your experiences with Parkinson disease, your attitudes and barriers to exercise, along with your interests in participating in home-based exercise. You will be asked to offer your opinions, but you do not have to offer any opinions that you do not want to. The interview will take about 90 minutes to 2 hours.

The interview discussion will be audio recorded to make sure that we accurately remember the content of the conversation. For this reason, you will be asked not to use your name during the interview; this is to make sure no one who sees information from this study later will know who you are. The second study staff member will also take notes, just in case there is trouble listening to the tape later. Then, a written record of the tape will be typed. The tapes will be erased after the transcriptions are completed. No names or any other information that could identify you will be put in the written record. The written reports from the tape will help the researchers to develop a possible future home-based exercise program.

After the interview is over, we will send you some additional questionnaires. We will also ask you to complete and return those questionnaires which ask more about your experiences with PD (either as an individual with PD or as a care partner), your relationship with each other, activities of daily living, balance and falls confidence, current participation in exercise, your interest for participating in a future home-based exercise program, as well as some detailed demographics and self-report health history information. It will take you no more than 90 minutes to complete these forms.

We will use the results of our discussions and your answers to the questionnaires to help us explore the possible development of an in-home exercise intervention delivered via telehealth for PD couples/care partners, and what needs you might have in order to participate in a future program.

Are there any benefits to me for being in this study?

You may not benefit directly from taking part in this study. However, this study may help create a home-based exercise program for dyads or couples living with Parkinson disease who lack access to exercise classes.

Do I have to be in the study? What if I say "yes" now and change my mind later?

No, you do not have to be in this study. Taking part in research is voluntary. This means that you decide if you want to be in the study. If you decide now to take part, you can choose to leave the study at any time. If one member of your dyad/couple opts out of the study, the other member of the dyad/couple may choose to continue participating or opt out, as well.

Let the researchers know if you choose to leave the study.

If you decide not to take part in the study, or if you choose to leave the study, your choice will not affect any treatment relationship you have with healthcare providers at UW-Madison, UW Health or any affiliated organizations, or any services you receive from them. No matter what decision you make, and even if your decision changes, there will be no penalty to you. You will not lose medical care or any legal rights.

Are there any risks to me?

Participation in this study involves being part of a discussion with a study staff member, and completing and returning questionnaires. While there are no anticipated physical risks to participants, there is a potential for a loss of confidentiality. Personal, sensitive, or identifiable information could become known to someone not involved in this study. If this happens, it could result in damage to your reputation, which could also affect your relationships with family and friends, affect your employment, or make it harder to get insurance or a job.

During the interviews and when completing the self-report questionnaires, some of the topics covered may be difficult to answer or may address sensitive topics. Obtaining information on sensitive topics may cause anxiety, distress, embarrassment, feelings of sadness, or discomfort. You may skip any question in the interview or the self-report questionnaires that you do not wish to answer. You may also withdraw from the study.

Will I be paid or receive anything for being in this study? Will it cost me anything?

You will receive a $50 VISA gift card for participating in this study. There will be no cost to you for any of the study activities or procedures.

How will my confidentiality be protected?

We have strict rules to protect your personal information. We will limit who has access to your name, address, phone number, and other information that can identify you. We will also store this information securely. While there will probably be publications as a result of this study, your name will not be used. Data other than recordings will be kept indefinitely for future research but this data will be stored without identifying information attached.

If you participate in this study, we would like to be able to quote you directly without using your name. Once we have finished reviewing the study information and consent form, we will ask if you agree to allow us to anonymously quote you in publications.

We cannot promise complete confidentiality. Federal or state laws may permit or require us to show information to university or government officials responsible for monitoring this study. This includes access to your medical records so that study monitors, auditors, the Institutional Review Board and regulatory authorities can verify study procedures and/or data. These groups will maintain your confidentiality. By agreeing to this consent form, you are authorizing this access to your records.

Who at UW-Madison can use my information?

- Members of the research team
- Offices and committees responsible for the oversight of research

Who outside the UW-Madison may receive my information?

- U.S. Office for Human Research Protections

Will information from this study go in my medical record?

- None of the information we collect for this study will be put in your medical record.

What if I have questions?

You may ask any questions about the research at any time. If you have questions about the research after we finish talking today you should contact the Principal Investigator, Dr. Kristen Pickett at 608-890-2103; or email her at kristen.pickett@wisc.edu or smil@education.wisc.edu

If you are not satisfied with the response of the research team, have more questions, or want to talk with someone about your rights as a research participant, you should contact the Education and Social/Behavioral Science IRB Office at 608-263-2320.

Agreement to participate in the research study

Your participation in this study is completely voluntary. You do not have to agree to participate. If you refuse, however, you cannot take part in this research study.

If you agree, it means that:

- You have read this consent form.
- You have had a chance to ask questions about the research study, and the researchers have answered your questions.
- You want to be in this study.

Your agreement indicates that you have read this consent form, had an opportunity to ask any questions about your participation in this research and voluntarily consent to participate. You have received a copy of this form for your records.

For completion by the person/interviewer obtaining consent:

Do you give your consent to participate in the study? ____ Yes ______ No

Do you give your permission to be quoted directly in publications without using your name?

____ Yes ______ No

Name of Participant (please print):____

Name of Person Obtaining Verbal Consent: ______________________________________

Date of Agreement: ____

Semi-structured Interview Questions & Guide -- Caregivers

Exploring Tele-Exercise for Rural Dwelling Dyads Living with Parkinson Disease

Hello. My name is (___________________). Thank you for taking time to talk with me today. I'm looking forward to our conversation, and really appreciate your willingness to participate in our study. I also have _____________ with me. S/he is going to help me by writing down notes from our discussion so that I don't miss anything that you say or forget any of the important things that I want to ask you. (*Give interview partner a chance to say "hello."*)

Today, I would like to have a conversation with you about your experiences as a caregiver/spouse/family member to your loved one with Parkinson disease and how it affects your daily life as an individual and your lives together.

I'd also like to discuss your thoughts and interests regarding an in-home exercise program for individuals with PD and their spouses/partners/family members.

Before we get started with the interview, I have a few questions for you.

Are you in a room where you feel like you can talk openly? And if not, can you go to a room where that allows you some privacy? The reason is that we might touch on some subjects that are more difficult to discuss freely. *(Be sure to note whether a private room is possible.)*

The next question I have before we get started…Did you receive the information sheet, also called the consent form that we sent you by mail? *(Go through consent form together.)*

Let's talk through it together, so that you have the information you need to decide whether you want to participate in the study.

Invitation: You've been invited to participate, because you're a family member to someone with PD, and you're interested in home-based exercise.

Purpose of the study: As researchers from UW-Madison, we're trying to figure out the best way to use telehealth to develop an in-home exercise program that works well for family care partners and their loved ones with PD.

Involvement: If you decide to participate, we'll go ahead and do this interview, which will take about 1 ½ to 2 hours. When we get to the halfway mark, I'll be sure to ask you if you need a break. But if you need a break beforehand, feel free to let me know.

I will be recording our interview and taking notes so that I can remember what we talk about. We'll also transcribe the interview to get it down word-for-word, but your name or any information that identifies you will not be put in the written record. Afterward, we'll erase the recordings.

Once the interview is finished, I will send you some questionnaires for you to complete on your own. It will take about 90 minutes to complete the forms. Then, you'll return them to me in a pre-addressed and stamped envelope.

Being in the study: Taking part in this study is completely voluntary. You can decide to take part or leave the study at any time. Whatever your decision, it will not affect any treatment options or healthcare that you're receiving.

Benefits: There may not be any direct benefits to you, but you will receive a $50 VISA card for participating. Plus, you're helping to provide important information that may lead to the development of a home-based exercise program for care partners and their loved ones with PD.

Risks: There are no physical risks to participating, but some of the topics we cover in the interview and the questionnaires may be difficult or sensitive to answer. You can skip any question that you do not want to answer.

Protecting confidentiality: Although we can't promise complete confidentiality, we have very strict rules and security procedures to protect your personal information. As I mentioned earlier, we will destroy the recording and eliminate your name and other identifying information (address, phone, etc.) from the written version of our interview, from the questionnaires, and from any publications that we write up to describe the study results. For any research articles that we do publish, we may use direct quotes from you, but again we won't use your name. And here in a minute once we've finished going through the consent form, I'll ask you if you agree to be quoted.

Who to contact with questions: If you have questions about this study at any time, you can reach Dr. Kristen Pickett or the IRB office. The telephone numbers are on the information sheet/consent form.

At this point, I'm going to start the recording of our conversation, and ask you about your agreement to participate in the study. *(Start the audio recorder.)*

Now that we've gone through the information sheet/consent form, do you have any questions?" (*Respond to participant questions.*)

Agreement: Do you give your consent to participate in the study called "Exploring In-home Exercise for Individuals with Parkinson Disease & Their Care Partners"? *(Wait for the answer).* Do you give your permission to be quoted directly in publications without using your name? *(Wait for the answer).*

(If the participant agrees to participate, begin the interview on the next page.)

*(If the participant, decides **not** to participate…)* **"Thank you very much for talking with me today and for your interest in our study. We will remove you from our call list at this time, but we do appreciate your consideration of this work."**

Thank you for agreeing to participate in the study. As I mentioned earlier, our talk today will last about 1 ½ to 2 hours. About halfway through, I'll suggest we take a break; but remember, you are welcome to take a break anytime you need one. Everything you tell me today will be kept completely confidential. I will summarize the things you tell me and combine it with other interviews that I will be conducting.

Your opinions are extremely important to the study, and you're the expert on your life and your experiences. I want you to feel free to tell me exactly what you think. Your participation is completely voluntary, and you don't have to answer any questions. If you would prefer to not answer a question, just let me know and we will go on to the next question.

Part I -- Canadian Occupational Performance Measure:

(Start with the COPM. The caregiver can focus on either their personal occupational concerns, or their caregiving concerns.)

Okay, let's get started. For this first part of the interview, I'm going to ask you to identify and prioritize everyday issues that are important to you, when it comes to things like self-care, productivity, and leisure time. As we go through these questions, I want you to think about things that you want to do, need to do, or are expected to do, but you can't do or you're not satisfied with the way you're able to do them. Think about all the different aspects of your life. These can be things that are specific to you individually or personally, or to your caregiving responsibilities.

Part II – Exploring Interdependence & Communal Coping:

Now let's shift our discussion a bit by talking about your experiences with your spouse's/family member's Parkinson disease. *(The following questions may have already been covered in the COPM interview. If so, use these to cover anything that was missed or needs more details.)*

1. **Tell me what a typical day looks like for you and (*name of loved one*).**

    a. **What kinds of things do you do to help him/her every day?** *(Probes: ADLs, hours per day providing help, physical assistance, doctor's appointments, driving, emotional and mental care)*

    a. **How does (*name – his/her*) PD and the things that you do to help him/her impact the things you personally want to do, need to do, or are expected to do every day?** *(Probes: household activities, work/volunteer, leisure, social, self-care)*

    b. **How does (*name – his/her*) PD affect the things the two of you do together – things you want to do, need to do, or are expected to do?** (*Probes: household activities, work/volunteer, leisure, social)*

2. **Are there things that the two of you do together to deal with the challenges of PD**? *(Probes: attend support groups together, go to the doctor together, exercise, learn more about PD, things*

you still do and strategies you've come up with to make it work)

3. <u>For de novo care partners</u>**: What are your concerns or worries about your spouse or family member's PD symptoms?** *(Probes: Motor Sx, non-motor Sx, balance, falls, cognition, disease progression, hospitalization, institutionalization)*

   a. **How do your concerns about your spouse and his/her symptoms affect you personally?** *(physical and mental health, balance, falls, ability to continue providing care, time and ability to take care of yourself, hospitalization, social isolation)*

   b. **How do your concerns or worries about PD affect the two of you together?** *(Probes: physical and mental health, relationship concerns, time and ability to care for/spend time with each other, social isolation, balance, falls, ability to continue providing care)*

   c. **How often do you talk about your concerns? How would you describe your discussions with each other?** *(Probes: easy/hard to talk to, back and forth sharing, one person does the talking, go around the subject)*

   d. **What motivates you to do what you do for (*loved one's name*)?** *(Probes: Is it love and the length of the marriage? Is it "just what you do b/c you're married"? Is it that there's no else to do it? Financial concerns? Happiness?)*

   e. **Earlier, we talked about the things you're doing to help *(name of loved one).* Are there things that might make it better or easier for you to be a caregiver? (***Probes: how to be a better caregiver, support groups, education about PD caregiving, respite, etc.)*
      - ○ Are there things he/she can or could do, or you wish they would do that would make it better or easier?
      - ○ Are there things you can do together, or are currently doing to make things better?

4. **Research has shown that caregivers often find it challenging to prioritize their own personal care and health. Tell me what you do to take care of yourself.** *(Probes: respite, exercise, self-care, get help (paid or unpaid), social support, etc.)*

   a. **How important is it for you to take care of yourself so that you can take care of your partner?**

   b. **How important is it for you and your partner to do things together to improve each other's health?**

That brings us to our half-way point in the interview, are you doing okay? Do you need to take a break to use the restroom, get something to drink or eat? *(Take a 5-10 minute break.)*

Welcome back! We're halfway through, but holler if you need another break. This next section of the interview deals with questions related to your community, as well as exercise. *Be sure to intentionally explore each of these prompts*.

5. **Most families living with PD, who live in Madison/larger city have easier access to a variety of resources to navigate the challenges of PD. Are there resources that you don't have that you wish were available, or easier to access in your community?** *(Probes: health care, social support, services, facilities, transportation)*

    a. How does the availability or lack of resources affect you as a caregiver living in your community/town? *(Probes: stress, time management, social support, reliance on family, proximity to family, economic burden)*

    b. How does the availability or lack of resources affect the two of you together when trying to deal with the challenges of PD? *(Probes: relationship strain, communications, strategies, reliance on family members, economic burden)*

6. We know that exercise is one way to improve health and well-being for caregivers. Tell me about your personal interests and experiences with exercise. *(Probes: exercise in the past or currently; perceptions of exercise, benefits/detriments, if no exercise, why not?)*

    a. **Have you ever started an exercise program, but were unable to continue it? What were the reasons why?** *(Make sure to explore barriers: individual factors, caregiving responsibilities, family and cultural views about exercise, economic factors, community resources and structures, work or employment)*

    b. Did you receive support from your spouse/family member(s)? If so, what kinds of support? Did that make it easier or harder for you to exercise? How so? *(Probes: encouragement/discouragement, motivation, keeping spouse occupied or safe, provided respite or travel)*

    c. **What about exercising together with your spouse/family member? Tell me about those experiences and your interests.** *(Probes: exercise in the past or currently, perceptions, barriers; if no exercise together, why not?)*

    d. **Earlier you told me about your daily routine, how do the things you do every day, including those as a caregiver for (name of loved one), affect your ability or willingness to exercise?**

    e. **You also shared your worries and concerns about (your loved one's) PD, how does that affect your interest in having him/her exercise? And how do those affect your interest in and willingness to exercise yourself? Or exercising together?**

    f. **Just a bit ago, we also talked about the community you live in and the resources you have available to help you with the challenges of PD. What's available in terms of**

exercise opportunities/facilities/classes?

And how does that availability or lack thereof affect your interest and willingness to exercise – either for you, your loved one, or both of you together?

7. **Have you ever participated in an in-home exercise program either for yourself or together with your spouse or family member?**

    a. **Tell me about the program and your experiences with it.** *(Probes: in-home exercise in the past or currently; perceptions of in-home exercise, benefits/detriments, if no in-home exercise, why not?)*

    b. **If it wasn't an in-home program, what was the program? Tell me about it**.

Part III – Process of Communal Coping & Telecycling Program Development

Now that we've talked about exercise, in general, let's talk in more detail about the possible development of an in-home exercise cycling program for care partners and their loved ones with PD. I mentioned it briefly during the review of the information sheet. (Skip the script for experienced CGs.)

> We're currently offering an in-home cycling program designed solely for individuals with PD. Here's how that program works: We bring a computer tablet and an easily accessible, recumbent bike to the person's home. The bike is about the size of two dining room chairs and has a nice wide seat. We set it up in a location in the person's house where it is safe and convenient for them to use. At the same time we set up the bike, we also set up the computer tablet and a Skype or Zoom account. Once we know everything is working, we schedule cycling sessions.
>
> During these sessions, the person with PD gets on the bike, then uses the computer tablet and Skype to visually connect with a partner from our research group, who also has a computer tablet and a bike. Together, they start cycling and talking to each other over Skype or Zoom. The research team member is usually an occupational therapy student, who guides and encourages the participant through the cycling sessions. Each cycling session lasts about 30 minutes and is done 3 days a week for 6 months. Our goal for that study is to find out whether an in-home cycling program, delivered via telehealth improves activities of daily living, quality of life, and balance for individuals with PD.
>
> During the first version of the cycling study, we heard from many spouses and family members that they would like to participate, as well. So now we're thinking about how we could include both the individual with PD and his/her spouse or other family member, and whether it's feasible to deliver a program like this with one bike and each person biking separately at different times.

This is where you come in to help us answer some of these questions. So thanks for hanging in there. The information you provide us today will help us possibly develop the future study.
(For ICP experienced caregivers, skip to page 11.)

For de novo care partners:

8. **We know that exercise is good for everybody, and caregivers who exercise show improvements in their health and well-being. So now that you've heard a little about the in-home cycling program for individuals with PD, how might it be beneficial for you?** *(Probes: physical, mental, scheduled exercise, a decrease in the amount of care provided, getting a break from your partner, hours to yourself, etc.)*

9. **We also know that exercise is good for people with PD by helping to improve their health, some of their symptoms, as well as some of their ability to do activities of daily living What do you think might be the benefits for your spouse to participate?** *(Probes: Improvements in Sx, ADLs, independence, etc.)*

   a. **Do you feel like this is something your spouse needs to do, or can do on his/her own?**

   b. **Do you think you'll need to help or provide support for your spouse/family member to participate?** (Probes: get on/off the bike, help your spouse prepare….)

   c. **Would you be willing to participate as a way to help your spouse, if it's beneficial to him/her?**

10. **Sounds like you think this program might be helpful for (*name of loved one*). If we're able to develop the program and both of you were to start exercising, how might cycling be helpful for you together?** *(Probes: things you like to do together, used to do together but can't do now – either because of PD or some other reason, your relationship, physical, mental)*

    a. **How would it be meaningful for the both of you to participate?**

    b. **And how confident are you that the two of you could participate in an in-home exercise program together?**

11. **If you were to help us design the program for caregivers and their loved ones with PD, what are some things that would be important to you?**

    a. **During our cycling sessions, we ask questions about how fast you're going, your heart rate, how you feel, and we "shoot the breeze." But we could also dedicate a portion of these sessions to providing you with some information.** *For example, the APDA has caregiving resources that we could share and talk about. They also have guidelines on exercise, and other information. Do any of those sound like something that would be helpful?*

12. **Tell me about the changes you would need to make to your daily life so that you and your partner could participate in an in-home cycling program, if we're able to offer it?**

    a. **Changes to your home** *(Probes: size of the bike, amount of space, location/placement, cords, internet connection)*

    b. **Is exercising on this bike going to add extra work for you?** *(Probes: fitting in 3 days/week, assistance to loved one, amount of help needed by spouse to participate, getting on/off the bike, using the tablet, connecting via Skype)*

    c. **What changes would you need to make to your caregiving and how you go about your day?** *(Probes: changes in daily care provided, getting spouse dressed for telecycling, working around medication schedules, household activities, personal activities, etc.)*

   d. **If we're able to develop the couple's cycling program, how will you and your loved one make the decision whether to participate?** *(Probes: one person will decide, both will decide, process to decide)*

   e. How will you coordinate with each other and work together to make the changes so you could participate in the cycling program?

   f. How do you feel about making these changes?

13. If we're able to offer the program, what do you anticipate doing while your spouse/family member is cycling for 30 minutes? *(Probes: household activities, rest, getting a break from your partner, hours to yourself, etc.)*

   a. Is 30 minutes for each session enough time to do what you want to do?

   b. If not, how much time would you want us to cycle with your spouse/family member so that you could do what you want to do?

   c. What concerns do you have about your partner's well-being while you cycle?

14. At this time and with what you know about the program, do you think you would be interested in participating in an in-home cycling program?

If they say yes: **What about it has particularly peaked your interest?"**

If they say no: **"OK, thanks, is there something that's getting in the way?**

   a. What kinds of resources or additional information would you need to participate or would encourage you to participate?

   b. **If an in-home cycling program is not the right thing for you, what kind of intervention would be of interest or helpful to you?** *(Probes: tele-support group with other caregivers or OT students, tele-education group with information about PD and caregiving)*

15. Thank you so much for your time today! It's really important to us that we develop this program in a way that is beneficial to you and relevant to people with PD and their care partners. You're are an important partner, because you're helping to inform the future development of this program. Is there anything else about exercise or the program that you'd like to talk about it?

16. **May we keep your contact information to call you in the future to let you know about program offerings?**

As a friendly reminder, we will send you some additional forms to complete and return in the mail. I'll call you again in about a week to see if you have any questions about the forms. You're also welcome to call me. I'll provide my contact information with the forms.

Again, thank you so much for chatting with me today!

For ICP experienced care partners:

7. **Back in 2019, you had experience with the in-home cycling program for individuals with PD when (partner's name) participated in it. Do you think the in-home cycling program was beneficial or detrimental or had no effect on your spouse? How so? *(Probes: Sx, ADLs, etc.)***

    a. Did you feel like the in-home cycling program was something your spouse needed to do on his/her own? Or did you help or provide support for your spouse/family member to participate (get on/off the bike, help your spouse prepare, was it extra work for you….)?

    b. How did your spouse's participation in the cycling affect you? *(time to self, time to get things done, changes in caregiving needs/responsibilities)*

    c. How did your spouse's participation affect both of you together, as a couple? *(Probes: physical, mental, things you like to do, used to do but can't do now – either because of PD or some other reason, your relationship)*

    d. If it had been an option at the time your spouse joined the program, would you have wanted to participate, too? And if so, how might cycling have been helpful for you personally?

8. **If you were to help us design the program for caregivers and their loved ones with PD, what are some things that would be important to you?**

    a. During our cycling sessions, we ask questions about how fast you're going, your heart rate, how you feel, etc. But we also chit chat, what would you like to talk about or learn about during our sessions?

    b. What would make the cycling sessions meaningful to you? *("shoot the breeze" for fun, time to chat about caregiving challenges, learn more about caregiving for someone with PD, etc.)*

9. **When (name) first began the program, what did you think about the program?** *(Probes: the length of the intervention, size of the bike, amount of space and location in home, ease of getting spouse on/off, safety, etc.)*

    a. Having the bike in your home and having your spouse /family member exercising every day for six months was a big commitment. Can you tell me about the changes your family made to your daily lives so that (name) could participate?

    b. Changes to your home *(Probes: size of the bike, amount of space, location/placement)*

    c. Changes to caregiving and your schedule *(Probes: fitting in 3 days/week, assistance to loved one amount of help needed by spouse to participate, changes in daily care* *provided -- getting spouse dressed for telecycling, getting on/off the bike, using the tablet, connecting via Skype, taking him/her to the lab for testing)*

   d. How did you feel about making those changes?

10. **While your spouse/family member was cycling for 30 minutes, what did you do during that time?**

    a. Was 30 minutes enough time to do what you wanted to do?

    b. If not, how much time would you have wanted us to cycle with your spouse/family member so that you could do what you wanted to do?

    c. If it had been an option for you to cycle, as well, what concerns would you have about your partner's well-being while you participated?

11. **If you could participate in a couple's version of the in-home cycling program today, tell me why you would or would not be interested in participating, and devoting the time to participate in the program.**

    a. Earlier I asked you about your concerns/worries about your family members PD symptoms? Would those concerns affect your interest in participating? How would your concerns or worries affect the ability for both of you to participate?

    b. What are activities you would like to see in such a program?

    c. What resources could the program provide that would help you decide to participate?

    d. Do you think you'd be willing and able to devote the time to participate in the program?

    e. If an in-home cycling program is not the right thing for you, what kind of intervention would be of interest or helpful to you? *(Probes: tele-support group with other caregivers or OT students, tele-education group with information about PD and caregiving)*

    f. May we keep your contact information to call you in the future to let you know about program offerings?

12. **Thank you so much for your time today! Is there anything else about exercise or the program that you'd like to talk about it?**
    As a friendly reminder, we will send you some additional forms to complete and return in the mail. I'll call you again in about a week to see if you have any questions about the forms. You're also welcome to call me. I'll provide my contact information with the forms. Again, thank you so much for chatting with me today!

Appendix F.2

Semi-structured Interview Questions & Guide – PD Care Recipients

Exploring Tele-Exercise for Rural Dwelling Dyads Living with Parkinson Disease

Hello. My name is (____________________). Thank you for taking time to talk with me today. I'm looking forward to our conversation, and really appreciate your willingness to participate in our study. I also have ______________ with me. . (*Give interview partner a chance to say "hello."*) She is going to help me by writing down notes from our discussion so that I don't miss anything that you say or forget any of the important things that I want to ask you

Today, I would like to have a conversation with you about your experiences living with Parkinson disease and how it affects your daily life as an individual and your life together with your spouse/partner/family member.

I'd also like to discuss your thoughts and interests regarding possible participation in an in-home exercise program for individuals with PD and their spouses/partners/family members.

Before we get started with the interview, I have a few questions for you.

Are you in a room where you feel like you can talk openly? And if not, can you go to a room that allows you some privacy? The reason is that we might touch on some subjects that are more difficult to discuss freely. *(Be sure to note whether a private room is possible.)*

The next question I have before we get started…Did you receive the information sheet we sent you by mail? *(Go through consent form together.)*

Let's talk through it together, so that you have the information you need to decide whether you want to participate in the study.

Invitation: You've been invited to participate, because you are a person with Parkinson disease, and you're interested in home-based exercise.

Purpose of the study: As researchers from UW-Madison, we're trying to figure out the best way to use telehealth to develop an in-home exercise program that works well for family care partners and their loved ones with PD.

Involvement: If you decide to participate, we'll go ahead and do this interview, which will take about an a 1 ½ to 2 hours. When we get to the halfway mark, I'll be sure to ask you if you need a break. But if you need a break beforehand, feel free to let me know.

I will be recording our interview and taking notes so that I can remember what we talk about. We'll also transcribe the interview to get it down word-for-word, but your name or any information that identifies you will not be put in the written record. Afterward, we'll erase the recordings.

Once the interview is finished, I will send you some questionnaires for you to complete on your own. It will take about 90 minutes to complete the forms. Then, you'll return them to me in a pre-addressed and stamped envelope.

Being in the study: Taking part in this study is completely voluntary. You can decide to take part or leave the study at any time. Whatever your decision, it will not affect any treatment options or healthcare that you're receiving.

Benefits: There may not be any direct benefits to you, but you will receive a $50 VISA card for participating. Plus, you're helping to provide important information that may lead to the development of a home-based exercise program for care partners and their loved ones with PD.

Risks: There are no physical risks to participating, but some of the topics we cover in the interview and the questionnaires may be difficult or sensitive to answer. You can skip any question that you do not want to answer.

Protecting confidentiality: Although we can't promise complete confidentiality, we have very strict rules and security procedures to protect your personal information. As I mentioned earlier, we will destroy the recording and eliminate your name and other identifying information (address, phone, etc.) from the written version of our interview, from the questionnaires, and from any publications that we write up to describe the study results. For any research articles that we do publish, we may use direct quotes from you, but again we won't use your name. And here in a minute once we've finished going through the consent form, I'll ask you if you agree to be quoted.

Who to contact with questions: If you have questions about this study at any time, you can reach Dr. Kristen Pickett or the IRB office. The telephone numbers are on the information sheet/consent form.

At this point, I'm going to start the recording of our conversation, and ask you about your agreement to participate in the study. *(Start the audio recorder.)*

Now that we've gone through the information sheet/consent form, do you have any questions?" (*Respond to participant questions.*)

Agreement: Do you give your consent to participate in the study called "Exploring In-home Exercise for Individuals with Parkinson Disease & Their Care Partners"? *(Wait for the answer).* Do you give your permission to be quoted directly in publications without using your name? *(Wait for the answer).*

(If the participant agrees to participate, begin the interview on the next page.)

*(If the participant, decides **not** to participate…)* "Thank you very much for talking with me today and for your interest in our study. We will remove you from our call list at this time, but we do appreciate your consideration of this work."

Thank you for agreeing to participate in the study. As I mentioned earlier, our talk today will last about 1 ½ to 2 hours. About halfway through, I'll suggest we take a break; but remember, you are welcome to take a break anytime. Everything you tell me today will be kept completely confidential. I will summarize the things you tell me and combine it with other interviews that I will be conducting.

Your opinions are extremely important to the study, and you're the expert on your life and your experiences. I want you to feel free to tell me exactly what you think. Your participation is completely voluntary, and you don't have to answer any questions. If you would prefer to not answer a question, just let me know and we will go on to the next question.

Part I -- Canadian Occupational Performance Measure:

(Start with the COPM.)

Okay, let's get started. For this first part of the interview, I'm going to ask you to identify and prioritize everyday issues that are important to you, when it comes to things like self-care, productivity, and leisure time. As we go through these questions, I want you to think about things that you want to do, need to do, or are expected to do, but you can't do or you're not satisfied with the way you're able to do them.

Part II – Exploring Interdependence & Communal Coping:

Now, let's shift our discussion a bit by talking more specifically about your experiences as an individual with Parkinson disease, and how it affects you and your spouse/partner/family member.

1. **Tell me what a typical day looks like for you and (*name of loved one*).** *(The following questions may have already been covered in the COPM interview. If so, use these to cover anything that was missed or needs more details.)*

    a. **How do your symptoms affect you on a daily basis?** *(Probes: ADLs, personal care, mobility, taking care of finances or things around the house, driving, physically, emotionally and mentally)*

    b. **What kinds of things does your spouse/family member help you with every day?** *(Probes: ADLs, physical assistance, doctor's appointments, driving, emotional and mental care)*

    c. **How do your symptoms affect the things the two of you do together?** *(Probes: things you like to do, used to do but can't do now – either because of PD or some other reason; household activities, work/volunteer, leisure, social)*

2. **Are there things that the two of you do together to deal with the challenges of PD?** *(Probes: attend support groups together, go to the doctor together, exercise, learn more about PD, things you still do and strategies you've come up with to make it work)*

3. **What are your concerns or worries about your PD symptoms?** *(Probes: Motor Sx, non-motor Sx, physical and mental health, balance, falls, ability to self-care, hospitalization)*

    a. **What are your spouse's/family member's concerns about your PD?** *(Probes: Motor Sx, non-motor Sx, physical and mental health, balance, falls, ability to self-care, hospitalization)*

    b. **How do your concerns or worries about PD affect the <u>two of you together</u>?**

    c. **How often do you talk about your concerns? How would you describe your discussions with each other?** *(Probes: easy/hard to talk to, back and forth sharing, one person does the talking, go around the subject)*

4. It's challenging for individuals with PD to do things to improve their health. Can you share your experiences with me?

    a. **How important is it for you to keep up your own health to be able to help your partner? And what makes it important?**

    b. What do you need to do to be able to take care of your partner?

    c. How important is it for you and your partner to do things together to improve each other's health? And what makes it important?

That brings us to our half-way point in the interview, are you doing okay? Do you need to take a break to use the restroom, get something to drink or eat? *(Take a 5-10 minute break.)*

Welcome back! We're halfway through, but holler if you need another break. This next section of the interview deals with questions related to your community, as well as exercise. *Be sure to intentionally explore each of the prompts.*

5. **Most families living with PD, live in larger cities, like Madison/larger city, so they have easier access to a variety of resources to navigate the challenges of PD. Are there resources that you don't have in your community that you would be helpful, or that you'd like to hae easier to access to?** *(Probes: health care, social support, services, facilities, transportation)*
    a. **How does the availability or lack of resources affect you as a person with PD living in your community/town?** *(Probes: stress, time management, social support, reliance on family, proximity to family, economic burden*
    b. **How does the availability or lack of resources affect the two of you together when trying to deal with the challenges of PD?** *(Probes: relationship strain, communications, strategies, reliance on family members, economic burden)*

6. **We know that exercise is one way to improve health and well-being for individuals with PD. Tell me about your personal interests and experiences with exercise.** *(exercise in the past or currently; perceptions of exercise, benefits/detriments, if no exercise, why not?)*

    a. **Have you ever started an exercise program, but were unable to continue it? What were the reasons why?** *(Make sure to explore barriers: individual factors, , family and cultural views about exercise, exercise habits, economic factors, community resources and structures, work or employment)*

    b. **Did you receive support or encouragement from your spouse/family member(s) to exercise? If so, what kinds of support? Did that make it easier or harder for you to exercise? How so?** *(Probes: encouragement/discouragement, motivation, keeping spouse occupied or safe, provided respite or travel)*

    c. **What about exercising together with your spouse/family member? Tell me about those experiences and your interests.** *(Probes: exercise in the past or currently, perceptions, barriers; if no exercise together, why not?)*

    d. **Earlier you told me about your daily routine, how do the things you do every day affect your ability or willingness to exercise?**

    e. **You also shared your worries and concerns about your PD, how does that affect your interest in and willingness to exercise? And how do those worries affect your interest in your spouse/care partner exercising? Or exercising together?**

    f. **Just a bit ago, we also talked about the community you live in and the resources you have**
    available to help you with the challenges of PD. What's available in terms of exercise opportunities/facilities/classes?

And how does that availability or lack thereof affect your interest and willingness to exercise – either for you, your loved one, or both of you together?

7. **Have you ever participated in an in-home exercise program either for yourself or together with your spouse or family member?**

   a. **Tell me about the program and your experiences with it.** *(Probes: in-home exercise in the past or currently; perceptions of in-home exercise, benefits/detriments; if no in-home exercise, why not? And other types of in-home programs?)*

   b. **If it wasn't an in-home program, what was the program? Tell me about it**.

Part III – Process of Communal Coping & Telecycling Program Development

Now that we've talked about exercise, in general, let's talk in more detail about the possible development of an in-home exercise cycling program for care partners and their loved ones with PD. I mentioned it briefly during the review of the information sheet. (Skip the script for IPDs who participated in the past.)

We're currently offering an in-home cycling program designed solely for individuals with PD. Our goal for that study is to find out whether an in-home cycling program, delivered via telehealth improves activities of daily living, quality of life, and balance for individuals with PD.

Here's how that program works: We bring an easily accessible, recumbent bike to the person's home. The bike is about the size of two dining room chairs and has a nice wide seat. We set it up in a location in the person's house where it is safe and convenient for them to use. We also provide a tablet that we set up so that the person can video chat with a member of our research team while they cycle. Once we know the bike and the tablet are working, we schedule cycling sessions at a time that's convenient for the person.

During these sessions, the person with PD gets on the bike, then uses the tablet to video chat with a partner from our research group, who also has a tablet and a bike. Together, they start cycling and talking to each other. The research team member is usually an occupational therapy student, who guides and encourages the participant through the cycling sessions. Each cycling session lasts about 30 minutes and is done 3 days a week for 6 months.

During the first version of the cycling study, we heard from many spouses and family members that they would like to participate, as well. So now we're thinking about how we could include both the individual with PD and his/her spouse or other family member, and whether it's feasible to deliver a program like this with one bike and each person biking separately at different times.

This is where you come in to help us answer some of these questions. So thanks for hanging in there. The information you provide us today will help us possibly develop the future study. (For ICP experienced individuals with PD, rewording of the question is in red. Be sure to add some details about their experience: e.g. when they biked, who they biked with, coming into the lab, etc.)

8. **We know that exercise is good for people with PD by helping to improve their health, some of their symptoms, as well as some of their ability to do activities of daily living. What do you think might be/were the benefits for you to participate in an in-home cycling program?** *(Probes: Improvements in Sx, ADLs, independence, etc.)*

    a. Do/Did you feel like an in-home cycling program is/was something you need or want to do on your own?

    b. **Do you think you will/Did you need your spouse's help or support to make it possible for you to participate?** (*get on/off the bike, assist with technology, safety concerns….*)?

    c. **We also know that exercise is good for caregivers helping them to improve their health and well-being. How do you think an in-home cycling program might be beneficial for your spouse/family member?** *(Probes: physical, mental, scheduled exercise, getting a break from caregiving, hours to his/herself, etc.)*

9. **Sounds like you think this program might be helpful for (*name of loved one*). If we're able to develop the program and both of you were to start exercising, how might cycling be helpful for you together?** *(Probes: things you like to do together, used to do together but can't do now – either because of PD or some other reason, your relationship, physical, mental)*

    a. **How would it be meaningful for the both of you to participate?**

    b. **And how confident are you that the two of you could participate in an in-home exercise program together?** *(Be sure to explore any barriers and facilitators.)*

10. If you were to help us design the program for individuals with PD and their loved ones/care partners, what are some things that would be important to you?

    a. **During our cycling sessions, we ask/asked questions about how fast you're going, your heart rate, how you feel, and we "shoot the breeze." But we could also dedicate a portion of these sessions to providing you with some information.** *For example, the APDA has resources that we could share and talk about. They also have guidelines on exercise, and other information. Do any of those sound like something that would be helpful?*

11. Tell me about the changes you would need to make/you made to your daily life so that you and your loved one/care partner could participate in an in-home cycling program, if we're able to offer it?

   a. **Changes to your home and schedule?** *(Probes: size of the bike, amount of space, location/placement, cords, internet connection)*

   b. **Is/Did exercising on this bike going to add extra work for you?** *(Probes: fitting in 3 days/week, amount of help needed to participate, getting on/off the bike, using the tablet, connecting via Skype or Zoom)*

   c. **If we're able to develop the couple's cycling program, how will/did you and your loved one make the decision whether to participate?** *(Probes: one person will decide, both will decide, process to decide)*

   d. **How will/did you coordinate with each other and work together to make the changes so you could participate in the cycling program?**

   e. **How do/did you feel about making these changes?**

12. **If we're able to offer the program for both of you, what do you anticipate doing while your spouse/family member is cycling for 30 minutes?**

   a. **Do you have any concerns about your well-being or safety while s/he participates?**

   b. **What concerns do you have about your partner's well-being while you cycle?**

13. **(Skip for experienced IPDs) At this time and with what you know about the program, do you think you would be interested in participating in an in-home cycling program?**

   a. *If they say yes:* **What about it has particularly peaked your interest?"**

   b. *If they say no:* **"OK, thanks, is there something that's getting in the way?**

   c. **What kinds of resources or additional information would you need to participate or would encourage you to participate?**

14. **Thank you so much for your time today! It's really important to us that we develop this program in a way that is beneficial to you and relevant to people with PD and their care partners. You're are an important partner, because you're helping to inform the future development of this program. Is there anything else about exercise or the program that you'd like to talk about it?**

15. **May we keep your contact information to call you in the future to let you know about program offerings?**

As a friendly reminder, we will send you some additional forms to complete and return in the mail. I'll call you again in about a week to see if you have any questions about the forms. You're also welcome to call me. I'll provide my contact information with the forms.

Again, thank you so much for chatting with me today!

Overarching Code	Initial Sub Code	Exemplary Quote	Definition	When not to use	Edited	Notes
Note: This version does not include any codes related to in-home cycling, sommunity, COVID, and eliminates all comm						
BEING A DECISION MAKER:	Handling things	24:04-CG#001: "I've told him, he can handle it and he does really fine with it."	The person describes the efforts/work that they do to manage a situation or take care of things.	Don't use if the participant refers to someone other than the partner as "handling things." (e.g. You know, our kids want to handle	7/10/2021	
	Reaffirming the care recipient's wishes	"You know I'm supporting you 100% but I want you to verbalize. I want this to be a conscious decision...not just something that's happening."	The person double checks or confirms what the partner wants in terms of his/her disease complications or health threats.			
	Standing one's ground or over-riding	"He said that he never wanted a feeding tube. So we were trying to honor that, and then, I decided he would." Another example -- "If he's not willing to fly, I can't drive that far. I can't drive that far!"	The person is adamant about something; or s/he makes a decision counter to what the partner wants or has said s/he wants; can also be noted by the partner			
	Trusting the person's capabilities (to build confidence)	"Sometimes he gets light-headed, and he sits down if it happens. And so, he's making good decisions about it." Another example: "I think that he's back now where if I couldn't do it, he would be okay."	The person refers to the partner's abilities to handle tasks or activities of daily living; suggests that the person is feeling more confident in the partner's capabilities.			

BELONGING:	Belonging or being included or being a part of something	"We love the group. And we just wanted people to feel like they belong. 'Cause you do feel different."	S/he describe the importance of belonging to a group, or the feelings derived from being included in a group. Can also describe a feeling of being excluded or not feeling like they belong.
COPING (INDIVIDUAL):	Using exercise	IPD: "I put a lot more intensity into my workout…I'm regarded as an overacheiver…and that helps my ego and helps me carry on through." Caregiver: I'm really concerned about his mental health when he can't golf anymore…because that's the thing that keeps him going."	The individual notes that exercise or physical activity provides a coping mechanism for them to handle stressors.
	Managing emotions	Caregiver: "I used to worry a lot and I still worry…but it's such a useless emotion…and you have a responsibility to manage it…"	The person indicates a need to keep their emotions "in check" to handle stressors; s/he may use
	Other mechanisms	29:42-CG#001: [In response to Netflix not working]"…especially when you're having a bad day."	This is a general reference to "external" coping mechanisms (such as television, or eating), if not explored fully.
	Role of Family	"I have a strong faith, and that helps me a lot, and the other is kids; I've got great kids." Another example: It's just not that my son isn't tremendously supportive, but he has his own fish to fry."	The individual mentions how family can either be helpful for alleviating stressors/offering support; or the family can be a source of stress.

	Spirituality	"I have a strong faith, and a great church. And that helps me a lot." Another example: "It's always been a real family faith, and it's been the backbone of our life."	The person mentions how their religious affiliation or sense of connectedness to a "higher power" or something meaningful helps them to handle stressors or brings up other emotions	Don't use if the person just mentions their religious affiliation or preference for that affiliation.		
EXERCISING:	Citing barriers	Caregiver: "I have a paddle board and two little sailboats that I love. But the water's been too high for me to take my sailboat out." IPD: "The road will get to be sheer ice before winter is done, and that's not safe for him to walk on."	Environment: time and weather; safety and physical limitations; other: comfort, boredom; lack of support, COVID???	Do not use when the participant references their PD Sx, CG health conditions, musculoskeletal limitations, or a health-related event as a barrier (e.g. the need to have a G-tube put in, or a recent bout of pneumonia, or a fall that caused injury). Instead use "Citing PD Sx or CG Health."	7/12/2021	LAPA and KLD need to go back and correct some of their codes, because they were generically using "citing barriers" when it should have been "citing PD Sx or CG health."
	<u>Subcode of citing barriers</u>: Citing motivation as a barrier or as something needed to participate	37:05-IPD "Sometimes for no good reason, I just, uh, sort of skip these things outside of the medication..." 1:05:07-IPD#001: "I could do it at home, but it's not the same. I need a lot more motivation." 01:21:16-PD#001: "I had to motivate myself to get on the weights..."	As a barrier, lack of motivation may be due to disinterest, or is consistent with PD; participant can also mention that s/he needed to "get motivated". **Both**	Don't use when the participant talks about someone other than themselves or their partner needing motivation to exercise. (e.g. "I've seen people fail at rehab because they weren't	7/12/2021	Added the "when not to use."

	<u>Subcode of citing barriers</u>: Citing PD Sx or CG health as a barrier	Caregiver: "I tried tai chi but I had to quit because my left leg….was hurting so bad by the end of the class." IPD: "It [exercise] was something we lost, when he was so weak and so sick."	The participant mentions either their own PD symptoms and/or caregiver health concerns as a barrier to exercise	Don't use if the health condition is mentioned outside the context of exercise.	7/12/2021	Definition was clarified.
EXERCISING: (cont'd)	Citing facilitators	1:03:31-IPD#001: "I put a lot more intensity into my workout than most people, and it makes me feel good that I'm regarded as an over acheiver."	Participant talks about things that make it easier to exercise or enjoying exercise and may mention reasons or the favorable outcomes (social aspects, opportunity to enjoy a favorite food, the type of exercise, competitiveness, etc.)		7/12/2021	Enjoyment and looking forward to were merged into this code
	<u>2nd subcode of citing facilitators</u>: Enjoying or feeling good (with "looking forward to" merged in)	1:03:31-IPD#001: "I put a lot more intensity into my workout than most people, and it makes me feel good that I'm regarded as an over acheiver." Another example: "…just exercising here at home and having him feel freeal good about it and being able to look forward to something that will be very therapeutic."	Participant talks about enjoying exercise and may mention reasons or the favorable outcomes (social aspects, opportunity to enjoy a favorite food, the type of exercise, competitiveness, etc.); also includes looking forward to exercise and regards the positive aspects or expectations the person has about participating in exercise (social, novelty, type of exercise, the act of exercising)		7/12/2021	Merged with citing facilitators as a 2nd level sub code

	Conflict/agreement btw partners	"I said, oh good, we can do the exercises together. He said, nah I won't exercise with you because you're too competitive."	The participant talks about how they agree or disagree with their partner about exercise; can include, but not limited to types of exercise each likes or is willing to participate in, whether to exercise, when to exercise, etc.		7/12/2021	Added an exemplary quote.
EXERCISING: (cont'd)	Doing ADLs and things around the house	1:18:23-PD#001: "As far as supplementing exercise sessions, I just use the activities of daily living." Another example: "I belive that a lot of your exercise comes from things that you are doing like cutting the grass, doing gardening…"	The participants talks about doing activities of daily living (chores, gardening, housecleaning, yardwork, etc.) as a means of exercise.	Don't use if the participant talks about doing ADLs, but hasn't mentioned them in the context of exercise. Instead use "managing daily routines and ADLs."	7/12/2021	Added the "when not to use."
	Encouraging and motivating the partner	1:21:46-IPD#001: There was some group sessions that she had been doing, that I, she sort of made me curous about it. And then I joined them."	The caregiver or IPD discusses what they do to encourage or motivate their partner to engage in exercise or physical activity; conversely, they may mention that they don't try to encourage or motivate.			
	Identifying types liked/disliked/never used	"I have some things I like to do like yoga and Tai Chi in particular. I did some Pilates but that was kind of repetitive and too much work." Another example: "He doesn't care too much for the repetitive online stuff [exercises]." He added: "I find my tolerance for online exercise sessions is less and less."	Participant mentions types of exercise that s/he prefers/doesn't prefer or hasn't tried previously; can also mention what the care partner likes, etc.	Don't use if the participant talks about an exercise that someone other than the care partner tried, liked, or disliked.	7/12/2021	Modified the definition to include types disliked, and added quotes.

	Important to physical and mental health	"I'm so glad that he is starting to exercise because I have missed it personally and I know that it's the only way he's going to get stronger."	The person may note that exercise is important to their physical and mental well-being, or to that of their partner.			
EXERCISING: (cont'd)	Modifying for self or partner	"I have those grippy things on his boots and his walking sticks. If it's slippery ice, I make him walk in the snow. I won't let him walk on the road." Another example: "If he ever gets one of those scooters someday, that's maybe a way tht we could get out and do that kind of exercise together again."	using equipment or making changes to the exercise(s) to accommodate a person or an injury, or to make it easier		7/12/2021	Added examples
	Participating alone	53:46-IPD: "Sometimes I'm sort of protective about that kind of stuff, and I just want to be alone and do the exercises that I feel are important."	The person indicates times that they exercise alone, or even a preference for exercising alone.			
	Participating in the past	1:20:2e4-PD#001: "Before I had Parkinson's disease late in my employment, I started working out at the Y by myself."	The person talks about participating in exercise or forms of physical activity they had engaged in at sometime in the past			
	Participating together	52:13-IPD: "She used to go with me to the gym, and they had the policy for this Parkinson's group that their care partner could participate also."	Participant mentions times that they engage with their partner; or they may mention a preference/dislike for exercising together as a couple.	Don't use if the person talks about exercising with individuals than their partner, such as family/friends in exercise		

	Readiness or contemplating participation	"I'm surprised he's interested in exercising, but he never has been before." Another example: "I haven't even suggested that we go back [to exercise],…'cause he's not ready yet."	This can include the person wanting to/being ready to exercise, or making a plan for exercise or physical activity; can also include not being ready for exercise or contemplating exercise If the participant is not currently exercising.	Don't use if the person exercises regularly. Instead use either "Participating Alone", "Participating Together", or "Therapy and Rehab Exercises".	7/12/2021	This code was merged with "Contemplating Participation", and the definition was expanded.
EXERCISING: (cont'd)	Receiving encouragement or support				7/10/2021	We differentiated two types of support for this code and added "From other family (not partner)" and "From the Partner".
	<u>Subcode of receiving support</u> -- "From the partner"	1:21:45-PD#001: "There was some group sessions that she thought quite highly of…she sort of made me curious about. And then I joined them."	The caregiver or IPD discusses what they do to encourage or motivate their partner to engage in exercise or physical activity; conversely, they may mention that they don't try to encourage or motivate.	Don't use if the person refers to others who supported, encouraged, motivated them; or who did the opposite -- discouraged, etc.	7/10/2021	
	<u>Subcode of receiving support</u> -- "From other family (not the partners), friends, or clinicians	"The doctor who did my surgery said, "walk, walk, walk, pedal, pedal, pedal."	The participant indicates that they have received support/encouragement/discouragement, etc. to exercise fom family (other than or in addition to the partner), friends, or clinician; or they indicate that family/friends share responsibility for the IPD's needs in order for the caregiver to be able to engage in physical	Don't use if the person refers to his/her care partner or spouse as the source of support or encouragement.		

	Therapy or rehab exercises	37:05-IPD "Once that's done, I try to do a, uh, if everything is going as I like to, take a voice training, speech training, swallowing training…" Caregiver: "I've recently been diagnosed with osteoporosis, so I've picked up some weight exercise and back rehab exercises."	Participant mentions exercises or rehabilitation therapies that they are doing to address PD symptoms; these may include "non traditional forms" of exercise, such as things like music therapy (diaphragm), swallowing training, voice training; can also included exercises adapted specifically for IPD (e.g. Rock Steady Boxing, Tango for PD, etc.)	Do not use if the participant doesn't mention it in conjunction with their symptoms for PD-specific concerns, or related to other musculoskeletal or rehabilitation exercises for both IPD and CG. Instead use "types like or disliked" and/or one of the "Participating in exercise" codes.	7/13/2021	Expanded the definition to include rehab exercises for other conditions in addition to PD, and made it applicable to both the IPD and the CG. Added the "when not to use."
FEELING:	A Sense of Urgency	Caregiver: "You're at a critical point here…You know you're at the brink."	The person notes that something needs a quick response, or immediate action.			
	Angry, annoyed, bothered, or irritated	1:01:45-IPD#001: "…sometimes I get a little irritated…a lot of times my anger is not at her but at the disease."	Indicating that someone, something or a circumstance makes the participant angry or irritated, etc.. Can also be the participant noting something or a circumstance as being annoying or bothersome.		7/13/2021	This code was merged with "Annoyed or Bothered", and the definition was expanded, given that the words are often used as synonyms.
	Burden or onus	57:36-IPD: "…as far as what the future holds for me and sometimes worries me, 'cause I don't want the care portion of it dumped on [my spouse]." Caregiver: "I have cried a lot of tears over it, but it's not something you can really even share easily with your family. I mean, it's mine."	The person describes something as being a duty or responsibility that comes with feelings of worry or can feel oppressive or overwhelming; The responsibility is his/hers to bear alone. **Caregiver;** This can also include the IPD being worried about putting burden on the CG. **IPD**		7/13/2021	This code was merged with "Onus", and the definition was expanded, given that the words are often used as synonyms.

FEELING (cont'd):	Compelled	24:04-CG#001: "At first when he started his tube feedings…I felt compelled to be there."	The person indicates they felt strongly obliged or that they had no choice but to do something		
	Confidence and self-efficacy	IPD: "It's important to do the stuff I can still do…I am still able to do it, and I try to do those things that I can." Caregiver: "He's got to take the taxes over to the accountant. He can do that…"	Participant expresses a belief in their capabilities or abilities to do something and to succeed at doing it.		
	Different or embarrassed	IPD: "Support groups they tend to be people in their 70s and 80s and I got Parkinson's at 51." Caregiver: "He's very self-conscious about his controlling the saliva. It's embarrassing for him."	Person describes a sense of being out of place or unlike others; can also relate to a change in feelings due to a circumstances or events. May also be due to having Parkinson disease and not being able to do things that they did before, or they feel like their symptoms cause them or others	7/13/2021	We merged "Embarrasment" into this code, and expanded the definition.
	Frustration	44:28-IPD: "I usually say to hell with it, and go and get [my spouse], and she can finish it off." Caregiver: "So I rehearse the conversation…because otherwise he gets real frustrated with me."	Anytime a participant indicates the they are unable to change or do something; or when a participant indicates problems when the spouse/partner is unable, unwilling, or lacking the motivation to change or do something.		

	Hope, joy, and gratitude	Caregiver: "I'm so happy that he wants to do it…I have some hope and he does too." IPD: "We've gone through 50 years of marriage…we work together as a team and for the most part it was a lot of un looking back at it…and it still is."	No explanation needed.	
	Lifting burden/freeing	Caregiver: "I think it's been somewhat freeing, having him use that and having a gauge to find out how he's feeling."	The person describes a feeling of having a "weight" removed due to some occurrence, or someone, or something; having obstacles removed; or a sense of freedom.	
	Sadness or depression	47:13-IPD#001: "Then I get uh, more than a little depressed."	The person can specifically mention "depression" or a feeling of sadness.	
FEELING (cont'd):	Worry	57:36-IPD: "My worries is, uh, what it'll [PD] end up to be…So there's a big question mark there as far as what the future holds for me and sometimes worries me."	Worry can be expressed as fear, concern, anxiouness, upset, etc.: can also be expressed as stress **Both CG and IPD**	
HELPING OR ASSISTING EACH OTHER (DYAD):	Relying on or depending upon or asking for help	45:07-IPD: "When I can't physically manipulate what needs to be done, so I have her do it. I tell her what to do and she would do it."	The person mentions that they can't do something, and need to ask the spouse/partner for help.	
	Stepping in	42:05-IPD "Just generally helping me with stuff that uh is a little harder for me to do…<u>**Usually sometimes I ask her, sometimes I don't**</u>**.** <u>**Then, she just comes in and helps me.**</u>**"**	Participant with PD notes that they receive help from care partner; the assistance is provided whether the person asks or not (almost as if it's "forced."); caregiver can also talk about it as having to be reactive as a way to control the	Don't use when the caregiver talks about having developed a strategy or

	Teaching	45:41-IPD: "I tell her what to do [to deal with a plumbing problem], and it's a new experience for her. And a new experience for me. It works out pretty well most of the time."	The individual guides/facilitates/or directs their partner how to do something new, or something that they used to do, but may not be able to, or are trying to encourage independence.			
IDENTIFYING:	Caregiver's health conditions	59:38-IPD: "She has her own problems also that she has to deal with. She has atrial fibrillation that she's taking care of and she's worried about a stroke too."	The caregiver mentions their own health conditions; or the IPD mentions the caregiver's health conditions.		7/11/2021	Changed code name from "Self or Partner's Health Conditions"
	Problems with sleep or feeling tired	Caregiver: "The sleep is more of a mental thing. I can't shut it down." IPD: "He would get exhausted so quickly…" Caregiver: "Sometimes I have to squeeze class in…it just depends on how zonked I am when I come home."	The person notes they have trouble sleeping and cite reasons for it. Or the participant indicates they feel tired, fatigued, exhausted, etc; they can also mention their partner feeling tired.		7/11/2021	This code was added because several CGs had indicated issues with sleep.
MANAGING	Managing daily routines and ADLs	24:04-CG#001: "I tidy up the kitchen. Get cleaned up for the day…" 37:05-IPD#001 "…run some errands, watch TV,	Can include reference to performing basic and instrumental ADLs, and leisure activities	When not to use: Anything related to PD Sx. Instead use: Progression of PD,		
	Role in the household	37:05-IPD: "I have to burn some of it [cardboard] so it doesn't get all cluttered up."	Individual describes what chores, tasks or responsibilities they hold in the house and the relationship.			

	Dealing with transitions/Parkinson's progression (strategies)	Caregiver: "First of all, he wasn't driving at that time. He needed me to drive him."	Actions taken to address changes related to progression of PD, can be an effective action or an ineffective action (ex. Effective: CG takes over the driving, ineffective: CG still allows the IPD to drive, but constantly backseat drives)	7/10/2021	We moved this code to become a subcode of "Managing", and added 2 subcodes to it.
MANAGING	Subcode of "Dealing with Transitions: "Not being ready"	Caregiver: "First of all, he wasn't driving at that time. He needed me to drive him." About an IPD: It was just the usual questions that I ask and she just wasn't ready for it."	Evaluation of the person's preparedness or readiness to engage in a specific activity, or a change, or deal with a transition .	7/15/2021	Clarified the definition.
	Subcode of "Dealing with Transitions: "Problem solving (strategies)	Caregiver: "There's a lot of things that are PD related…I'm working through problems, like 'How are we going to have this conversation."	"The person describes the need to solve problems, or the process they go through to take care of something.	7/15/2021	Added to "Dealing with Transitions, b/c many CGs, in particular, talked about their problem solving to deal with the transitions.
MANAGING MEDICAL NEEDS:	Administrative and logistical	EX. Pg. 15/16: 35:38: "And I just have a, I actually have a spreadsheet that I made and I put everything on. "	tasks related to managing and coordinating the scheduling and needs of either member of the dyad, can include making appointments, keeping track of finances, medications, insurance; **both**		
	Advocating and/or accompanying	00:37:35 PD #001-CG: Well, he didn't need a lot of things to begin with. Now he's, um, you know, if he had to do it, I'm sure he could. At this maybe, at this point, I'm sure he could. But he's, you know, gotten used to me taking care of the meds, and that kind of thing."	Asking on behalf of the other person to receive services, gain access to opportunities, or be their voice, **o**r maintain their self identity; often includes accompanying someone (such as to medical appointments.)		

	Influence and involvement of family	16:49-CG#001: …but my role with him is different than his son's role is…[in reference to G-tube]; 26:55-CG#001: "My son talked to him, and he decided he would…[in ref to G-tube]."	The role or inclusion of family in making medical decisions that may impact the health of the recipient.			
	Interacting with or identifying needs within health care system	Ex. Pg. 15 33:13: " I felt like there were changes in his Parkinson's and he needed someone who focused on Parkinson's disease. He needed a movement disorders specialist, a neurologist."	Includes both positive and negative interactions with healthcare providers (can also include insurance related providers) or identifying the types of providers needed to address concerns	Don't use if the person is talking about taking medications; instead use "Controlling PD Sx". Don't use if the person refers to doing therapy (unless the therapy is in a clinic or telehealth visit, and supervised by a clinician); instead use "EXERCISING/Therapy or Exercises."	7/16/2021	Refined the definition to include "when not to use" examples.
	Planning for the future	Ex. 35 5:14: If something goes haywire…I would probably have to call Bellin if I needed, if we ran out of tube feedings for some horrible reason."	Needing to consider different scenarios or possiblilties when planning for future emergencies or events; can apply to the immediate, medium, or long-term future. **only CG or both?**			
MINIMIZING:	Flip-flopping	Caregiver: "But I talked to my doctor. So I feel like its pretty well under control. I don't think there's anything I'm not doing…Well probably there are because I won't go in and have a colonscopy."	Contradicting oneself, as in saying one thing and then switching to another story or description of an event or reasoning with the purpose of protecting, not sharing, perception, or other undisclosed reason, **can apply**			

	Sacrificing, downplaying or neglecting self care	14:27-CG#001--"Sleep has been kind of an issue for me lately...but I guess I don't really ever let it bother me....nobody died of lack of sleep." "and so they're not coming into this test. And you know, so yes, I was moving forward with it and totally plan to do it. PD #001-IPD hadn't...PD #001-IPD had gotten over pneumonia by then, and um but he hadn't started this whole swallow cycle thing that didn't come until...April "	1) Sacrificing: Taking an action for somebody else that results in CG's injury or harm 2) Downplaying -- The person negates or minimizes the importance of their own health and health behaviors. Or s/he minimizes health related events, or delays going to the doctor; and 3) Neglecting -- Inaction or postponing care, can possibly relate to both CG and IPD?			
	Sense of self	CG-19:43: "I've always been a little overweight…I would tease my kids that I was the strongest fat lady." Another example: "And then he says, 'you're overreacting.' And I said [IPD's name], we could have died."	Comparing in a negative way individual's personal skills, qualities, or overall image of self, or his/her partner's. **both**		7/15/2021	Added that the negative comparison could be coming from the spouse.
PRIORITIZING:	CG health	9:30:"it's important that I stay strong 'cause I can't help him if I don't." Another example: "I have a bad shoulder, so I'd have to special exercises for that."	Recognizing the importance of the CG's health; can have to do with taking an action or also just identifying it as an important element to either party. **both**			
	Doing things together	43:13: "I think just being able to do it together again, we've you know, especially in retirement, we've done so much together it's...We've enjoyed a lot of the same things "	Valuing doing a variety of things together, examples can include traveling, going to restaurants, attending support groups, but are not limited to it, **both**	Do not use when the participant talks about exercising together with her/his partner. Instead, use "EXERCISE/Participating together."	7/15/2021	Omitted physical activity and referenced the correct code.

	Self needs and/or insisting on independence	18:58-CG#001: " I found a league that played in the afternoon and so it was kind of a good time." 01:23:26-PD#001: "…when I do it is when I wanna do it. Not when somebody tells me to do it."	Taking actions on one's own for personal needs or desires, for example seeking out own activities, **ONLY applies to the CG**		We also have the code "Insisting on Independence" in Progression of PD. We need to address how these two are different.
PROGRESSION OF PD:	Admitting or moving toward acceptance; (Note: These two codes were merged in Nvivo.)	Ex. P.9: "Eventually…our house isn't going to meet our needs much longer." IPD 43:59: "Sometimes I get tired or just don't feel comfortable doing it. I let her take over." 33:13-CG#001: "Well, he always had more trouble with the swallowing, but it became more intense."	The person acknowledges or is uncomfortable that something has changed or is going to change. **both**	6/23/2021	
	Being strong = being healthy	0:9:30-CG#001:"So, so being as strong as he can is really important, and it's important that I stay strong 'cause I can't help him if I don't." 1:56:28-PD#001: "I would build up strength and help address some of that Parkinson symptoms that I havse that are occurring	Participants acknowledgement that being strong (physically **or otherwise**) is a sign of health, Can apply to either IPD or CG		
	Contrasting/comparing/ reclaiming the past	Ex. "you know get back in shape, get strong…ummm reclaim whatever you can."	Wanting or the desire to return to a past self or past concept of how things were, **both**		
	Subcode of "Contrasting" -- Still doing or holding onto things	1:06:21-IPD#001: "It's important to do the stuff that I can still do, like I can still shovel snow, and hold onto it. I try to do those that I can."	The person emphasizes skills or activities or things that they feel they can still do, or should still do.	7/10/2021	We moved this code to become a subcode of "Contrasting, Comparing, Reclaiming the Past"

PROGRESSION OF PD (cont'd):	Controlling PD and the Sx	Ex. P. 19 43:22: "Yes he, I mean he'll admit that sometimes he gets lightheaded, and he sits down if it happens. And so, he's making good decisions about what to do about it."	Actions related to self managing or having others manage sysmptoms related to PD, **only for IPD?** Routine for PD and what they are doing daily/weekly/monthly.		
	Denying or shifting blame	30:49: He wasn't comfortable with his driving...he thinks he needs to have his glasses changed.	The person denies that PD (or another health concern) is the problem; or s/he shifts the blame to something or someone else		
	Getting stronger	Ex. P. 18: "it's something that we lost, when he was so weak and so sick, but now he's getting stronger."	The idea of moving towards a healthier state after a major health event/decline/ change related or not related to PD, **can relate to CG or IPD**		
	Identifying/acknowledging PD symptoms	46:51-IPD: "There's salivation, swallowing, change in voice...constipation is one I forgot that is very real."	The person IDs they're own Sx; or the partner does		
	Subcode of ID'g PD Sx: The shift	Caregiver: "He never had a problem communicating...Now I literally have to stop and thing: 'how can I say this?" and not lose him completely."	The cause for a change in routine, identifying a scenario that had a drastic change in their daily routine	7/10/2021	We incorporated this code as a subcode of "Identifying or acknowledging PD Sx."
	Insisting on independence	1:23:26-PD#001: "...when I do it is when I wanna do it. Not when somebody tells me to do it."	Participant wants to do something without assistance or being told to do something. **Only applies to the IPD**		See comment above on "IDENTIFYING/Self needs and independence."

PROGRESSION OF PD (cont'd):	Losing something cared about	Caregiver: "We would play cards with my family...but it's difficult because he has symptoms he's self-conscious about." IPD: "Playing instruments I've done without it, but I'd reallly like to do it, but it just doesn't seem to be working."	Losing some type of skill, past activity, hobby that was present before the disease; Losing something due to disease progression or health threat		
	<u>Subcode of "Losing Something Cared About</u>: Losing strength/ground	32:14-CG#001 -- "He lost a lot of ground."	Person refers to a loss of strength or capabilities because of a health problem; **both**	7/10/2021	This code was merged as a subcode of 'Losing Something Cared About."
	<u>Subcode of "Losing Something Cared About</u>: Losing or gaining self-esteem	36:12-CG#001: His loss of muscle mass and stuff, I mean his self esteem has really been affected by the loss of muscle mass." 1:04:07-IPD#001: I'm regarded as an over acheiver, so that helps my ego a little bit and helps me carry through."	Losing or changing self concept in a negative way, due to changes associated with PD; but can be the opposite such that something makes the person feel good or gain self-esteem; **applies to both**	7/10/2021	This code was merged as a subcode of 'Losing Something Cared About."
	Managing the routine of PD	35:43-IPD "My first activity of the day is getting set up, taking medication and getting set up for my first feeding in the morning through the gastric tube."	The participant describes the routine(s) they go through to manage PD symptoms, **both**		
	Not being ready	26:26" He wasn't ready, he was too weak. His balance wasn't good. And I didn't want him to feel pressured into it. You know that."	Evaluation of the persons preparedness or readiness to engage in a specific exercise, activity, or otherwise, **both**		

	Pushing decision making of IPD	?15:35: "but he had previously made the decision not to have a G tube and I did everything in my power to respect his decision." **I am not totally sure on this one**	Encouraging or insisting that the IPD make their decision about an event,		
PROGRESSION OF PD (cont'd):	Staying on track	9:04:"I think the short term is keeping PD #001-CG and track and trying to help him get stronger"	An act of attempting to maintain the IPD on a certain path of health, may be associated with what the CG predicts what will happen to IPD		
	Uncertainty of the future	57:36-IPD#001: "There's a big question mark there, as far as what the future holds for me."	The participant expresses concern about the progression of PD and how it will affect them (or present as symptoms) at some undefined point in the future.		
	Watching from behind (looking out for each other); vigilance	38:24-CG#001: "you're not 20 years old anmore, you gotta pace yourselef…so I just I get, I guess I've gotten used to kind of used to watching him from behind." 26:55-CG#001: "When he was so ill...I was sleeping so lightly…but I was always listening." Another example: "You know, we try and work	The idea that the partner is monitoring the other to keep them safe or healthy, can be related to PD or not; **can apply to either CG or IPD**	7/11/2021	Note: This code was moved out of Relationship Functioning for the purpose of KLD's dissertation, because it demonstrates the perception of PD as a threat to the dyad.
SOCIALIZING:	Enjoying interaction	54:57-IPD: "…the groups seem to hit it off between each other very well... [56:07] everybody seems to enjoy the interaction."	Participant talks about how they enjoy engaging with a group, and the group dynamics.		

	Isolation	"In all the years we've been here, we really don't socialaize that much."	Lack of interaction with peers, neighbor, people outside of family.	Don't use when the participant is talking about the physical location of their home or community causing them to feel isolation.	7/11/2021
	Minimizing Importance of social	Ex: 46:37: "I don't think we had a huge social life. The last few year, our gym, going to the gym was probably the biggest social thing that we did, besides seeing her kids."…48:16, I don't have a lot of social needs"	Denying or opposing past importance or emphasis on social life, **CG and IPD**		
SOCIALIZING:	Prioritizing importance of social	54:40-CG: "Sharing with this group is really important" 52:13-IPD: "It's a good exercise session, but a good sesssion to show off our social skills."	Recognizing and highlighting the value they place in creating connections with other, **both**		
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