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## Exploring the Burden Experiences of Care Partners for People with Parkinson's Disease Living in Southwestern Ontario

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## Abstract

This thesis quantitatively explored the burden experiences of care partners of people with Parkinson's Disease in Southwestern Ontario. Thirty-five complete responses (27 females, 8 males) and three partial responses to an online survey were obtained. The survey included a demographic section (41 items), two measures of burden and a quality of life measure. Care partner data were stratified based on Zarit Burden Inventory scores for analysis. Of the Little to No Burden (n=8), Mild Burden (n=15), Moderate Burden (n=8), and Severe Burden (n=4) groups, weekly hours spent on care duties and years in the care partner role were similar. The Severe Burden group provided most assistance with toileting ( $p=0.0007$ ), eating ( $p=0.0037$ ), dressing ( $p=0.0099$ ) and bathing ( $p=0.0076$ ), when compared to the Little to No Burden group. The Severe Burden group also accessed significantly more formal assistance compared to the Moderate and Little to No Burden groups.

### Keywords

Care partner burden, caregiver burden, quality of life, activities of daily living, Parkinson's disease, care partner, caregiver

## Summary for Lay Audience

Parkinson's Disease (PD) can impact a person's independence and participation. Most often, those closest to a person diagnosed with PD (PwPD) take on responsibilities to accommodate for this loss of independence. In taking on such responsibilities, they are considered care partners to the PwPD. Negative experiences of stress related to this role are referred to as burden. This thesis reports on 35 (27 female and eight male) complete and three more partial (two female and one male) care partner responses to an online survey to characterize the burden experiences of care partners in Southwestern Ontario. Overall, 31.6% of the care partners in the sample experienced at least moderate burden. Care partners experiencing the most burden reported helping the PwPD in their care with bathing, dressing, toileting, and eating more than care partners experiencing the least burden in the role. Importantly, the hours per week spent providing care to the PwPD and the number of years in the care partner role was not statistically different when comparing care partners based on the degree of burden they experience. Of those surveyed in this study, male care partners reported higher burden when compared to female care partners. Overall, these findings are an important step in characterizing care partner experiences related to PD in Southwestern Ontario and offer relevant information to clinicians and community partners concerned with care partners or with PD in this region.

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# 1 Introduction

Parkinson's disease (PD) is the second most common neurodegenerative disease in Canada and is characterized by the following motor symptoms: bradykinesia, postural instability, rigidity, and tremor (Jankovic, 2008). Non-motor symptoms such as sleep disturbances, dementia, chronic pain, apathy, psychosis, and difficulties with mood regulation (including clinical depression and anxiety) often accompany motor deficits (Park & Stacy, 2009; Aarsland et al., 2010). As such, PD can result in a loss of independence, as activities of daily living become progressively more physically and mentally challenging for those diagnosed (Van Uem et al., 2016).

PD is most often diagnosed in individuals over age 60 (Tysnes & Storstein, 2017), while only 2-10% of people living with Parkinson's Disease (PwPD) worldwide are under 50 years of age (Tysnes & Storstein, 2017). Over 100,000 Canadians live with the disease, and approximately 5,500 new diagnoses of PD are made every year (Grimes et al., 2012). Due to population ageing, the annual number of new diagnoses is projected to increase over the next two decades (Marras et al., 2018; Rossi et al., 2017; Wirdefeldt et al., 2011). As there is no cure for PD, available treatment options target the progression of individual symptoms and rehabilitation strategies address limitations in activities of daily living, to improve PwPD quality of life (Van Uem et al., 2016).

As the majority of PwPD live in the community (Wong et al., 2014), those closest to them, most often spouses and adult children, take on responsibilities of care and support (Goy et al., 2008). These individuals who take on such physical, social, and psychological support duties are referred to as care partners and are an integral yet often underserved community, whose contributions represent a facilitator of treatment and quality of life for PwPD (Goy et al., 2008). Care partners have also been historically referred to in literature as "caregivers", "informal caregivers" and "carers". However, the term care partner has been gaining popularity in use as it better recognizes the agency of the PwPD within the care dyad and acknowledges the role the PwPD has in their own care decisions (Bennet et al., 2017). As such, the term care partner will be used in this thesis.

McLaughlin et al (2011) estimated that over 60% of care partners for PwPD spend over 50 hours per week performing duties related to care. As the disease progresses, PwPD often become less independent and require increased care and assistance with activities of daily living (McLaughlin et al., 2011). While some studies have described positive aspects of occupying a care partner role such as increased sense of purpose in the care partner's life and improved family relationships (Konstam et al., 2003; Barken, 2014), care partners have also reported decreased capacity to engage in their own meaningful pursuits or in self-care and health maintenance, leading to negative outcomes (Theed et al., 2017, Mosley et al., 2017). Specifically, the presentation of care partner burden, a subjective experience of stress and burnout arising from providing informal care, has negative consequences for the care partner and for the PwPD (Mosley et al., 2017; Bhimani, 2014). Health consequences of care partner burden on the care partner include fatigue, weakened physical health and immune function, decreased quality of life, increased mortality and development of mood and anxiety disorders (Mosley et al., 2017; Bhimani, 2014). For example, between 12% and 50% of care partners of PwPD meet the diagnostic threshold for depressive and anxiety disorders (Mosley et al., 2017). Importantly, sustained care partner burden is strongly associated with institutionalization of PwPD, a widely undesirable outcome in older adult care (McLennon et al., 2010; Abendroth et al., 2011).

The presence of neuropsychiatric symptoms in the PwPD receiving care, including depression, anxiety, apathy, fatigue, and psychosis, is one of the most significant contributors to care partner burden (Schrag et al., 2006). For example, a PwPD experiencing anxiety over the possibility of falling while their spousal care partner is not in their presence may become distressed by their care partner wanting time to themselves. As a result, the care partner may take less time when participating in their own activities, while experiencing guilt and tension within the relationship. This dynamic may be especially problematic if the care partner experiences their own health issues and hesitates to attend to their own healthcare needs. Moreover, since current medical interventions of PD primarily focus on managing motor symptoms, treatment for the PwPD may not provide relief for care partners who are struggling within the role as a consequence of non-motor symptoms (McLaughlin et al., 2011).

Other factors mediating burden in the care for PwPD include care partner self-efficacy, stemming from access to training and information on care partner duties (Yang et al., 2019; Park



et al., 2019), and the presence or lack of social support (Dunk et al., 2017; Grun et al., 2016). Some research groups have developed educational programs to address care partner self-efficacy (A'Campo et al., 2010) and support group programs to increase feelings of social support (Shah et al., 2015). Importantly, the impact of type of programming has not been studied in the Canadian population of care partners for PwPD. Since the social care and healthcare systems relevant to PwPD and their care partners vary across regions (Mateus & Coloma 2013), needs assessment data must first be gathered to inform care partner resource development and further care partner resource implementation. In this way, a preliminary needs assessment relies on an understanding of the experiences of burden present in the relevant population and the most prevalent factors contributing to burden in that population of care partners (A'Campo et al., 2010; Shah et al., 2015). Due to limitations in medical professionals' time and training, care partners' needs and wellbeing outcomes are not assessed at an individual level through the PD treatment process. As a result, a gap exists in the identification of care partners who are struggling within the role and the understanding of their specific needs.

Currently, no needs assessment is available pertaining to the needs of care partners for PwPD living in Southwestern Ontario and their experiences have only been studied once directly (Roland et al., 2010). In 2010, Roland and collaborators reported the psychological aspects of the care partner role for five female participants living in Southwestern Ontario. Their findings suggested that social isolation and concern for the safety of the PwPD were primary mental stressors. Recommendations were made advocating for more education to be directed towards coping with these mental stressors. While these findings present an important starting point to address the needs of this population, they may not be representative of the current needs of care partners of PwPD in Southwestern Ontario. Moreover, as the participants were all spouses of the person receiving care and female, the results do not capture the experiences of other care partners for PwPD living in the region. As such, the overarching goal of this survey research study was to explore and describe the unique burden and unmet support needs experienced by care partners of PwPD living in Southwestern Ontario, in order to inform the development of resources for this specific population.

## 2 Literature Review

To situate the present research, this literature review will: describe the impact of Parkinson's disease (PD) on individuals experiencing the disease and their care partners; summarize the development of care partner burden as a measurable and clinically relevant entity; and outline the specific characteristics of negative care partner experiences in PD. Factors contributing to the development of care partner burden and related outcomes will be outlined to present the multifaceted nature of care partner experiences. As the overarching goal of this research moving forward is to inform the development of resources for care partners, studies of care partner burden interventions will also be discussed.

### 2.1 Parkinson's Disease

PD is characterized by neurodegeneration causing progressive loss of motor function and in many cases, also involves a progressive increase in non-motor complications (Park & Stacy, 2009; Aarsland et al., 2010). The motor symptoms of PD are caused by the progressive death of dopaminergic neurons in the substantia nigra of the midbrain, resulting in depressed dopamine levels in motor pathways (Dexter & Jenner, 2013). Current pharmacological approaches target dopamine production and uptake, and thus address the motor symptoms of PD (Cheong et al., 2019). Current gaps in understanding of the mechanisms for the development of non-motor symptoms, especially neuropsychiatric symptoms, make treatment of these facets of the disease less efficacious (Titova & Chaudhuri, 2018).

The clinical course and severity of PD are commonly assessed using the Movement-Disorder Society's-Unified Parkinson's Disease Rating Scale (MDS-UPDRS) (Goetz et al., 2007) and the Modified Hoehn and Yahr Scale (H&Y) (Goetz et al., 2004). The MDS-UPDRS has four parts: part I evaluates non-motor symptoms, part II is a self-reported evaluation of activities of daily living (ADLs) such as speech, walking, swallowing, and hygiene, part III assesses motor function and part IV evaluates motor complications, such as dyskinesia. In contrast, the Modified Hoehn and Yahr Scale (Hoehn & Yahr, 1967; Goetz et al., 2004) categorizes the progression of PD into seven stages, based on the presented motor symptoms and functional disability. Stage

one is characterized by mild unilateral involvement, with little to no functional impairment. Stage 1.5 is characterized by unilateral and axial involvement. Stage two is characterized by bilateral involvement, where facial muscles become involved, leading to small functional impairments such as decreased blinking and slurring speech. Stage 2.5 is characterized by bilateral involvement with some postural instability. Stage three is characterized by the presence of bradykinesia and postural instability, but maintenance of some functional ability such that the person with PD (PwPD) is still independent in most ADLs. Stage four involves disabling motor symptoms, and a lack of independence in many ADLs. Stage five is the most advanced stage, involving inability to stand independently without falling, and a lack of independence in most ADLs. Notably, both of these scales reflect the functional implications of living with PD, and the broad impact PwPD experience in their independence and ability to participate in everyday activities.

### 2.1.1 Strategies for the Management of PD

Treatment options available for PwPD target the progression of the disease based on clinical symptoms (Van Uem et al., 2016). As the motor symptoms of PD are mechanistically better understood and lead to measurable functional impairment, these symptoms are primarily targeted therapeutically. While the Canadian Guidelines on PD treatment recommend the use of dopamine agonists for the first line treatment of motor symptoms (Grimes et al., 2012; Grimes et al 2019), dopamine agonist efficacy decreases overtime and impulse control disorders are reported to occur in up to half of PwPD using dopamine agonists long-term. Levodopa, another therapeutic agent, is metabolized directly into dopamine when given in combination with carbidopa (Sinemet) or benserazide (Prolopa) and is considered the most effective pharmacological treatment of PD motor symptoms (Grimes et al., 2012; Grimes et al 2019). Similar to dopamine agonists, however, the efficacy of levodopa decreases over time and causes side effects including nausea, low blood pressure, dyskinesia, and psychosis (Grimes et al., 2012; Grimes et al 2019). Due to the severe dyskinesia that may manifest as a side effect from long term use of levodopa, this drug is not used as a first line treatment for PD (Grimes et al., 2012; Grimes et al 2019). Beyond pharmacological interventions, deep brain stimulation of the subthalamic nucleus is also utilized to minimize motor symptoms in those who do not or no

longer respond to pharmacological interventions (Grimes et al., 2012; Grimes et al 2019). Side effects from deep brain stimulation treatment include hypomania, depression and apathy, and impulse control challenges (Cyron, 2016). It is noteworthy that many of the side effects of motor symptom-focused treatments can be neuropsychiatric and can exacerbate non-motor symptoms that already may present as a part of PD (Aarons et al., 2012; Cryton, 2016). Furthermore, deep brain stimulation is a limited treatment option, due to extensive requirements for PwPD to qualify for the procedure (Lang & Widner 2002; Lachance et al., 2018).

To treat the non-motor symptoms of PD, several diverse interventions may be used. Cognitive-behavioural therapy and pharmacotherapies are recommended for neuropsychiatric symptoms, such as anxiety, depression, psychosis, and impulse control disorders (Grimes et al., 2012; Grimes et al., 2019). Pharmaceutical therapies for neuropsychiatric symptoms of PD must be carefully considered in light of possible interactions with other prescribed medications in order to avoid adverse effects and decreased treatment efficacy (Grimes et al., 2019; Goodarzi et al., 2018). Furthermore, referrals to these treatments are made less frequently, as some physicians have reported lack of confidence in the available research supporting these treatments and discomfort in using suggested screening tools (Goodarzi et al., 2018). Such conflicts make navigating the health care system as a PwPD more difficult (Goodarzi et al., 2018).

Rehabilitative strategies for continued participation in activities of daily living for PwPD include physical and occupational therapy, and speech language pathology (Grimes et al., 2019). While there has not yet been a study on rehabilitation service utilization in PwPD in Canada, data from the Netherlands, Czech Republic, USA, and South Korea indicate that PwPD frequently do not access the rehabilitation treatment options outlined by clinical practice guidelines (Gal et al., 2017; Keus et al., 2004; Fullard et al., 2017; Seo et al., 2018). However, these treatments have been identified as effective in maintaining functional independence for the PwPD and increasing PwPD quality of life (Abbruzzese et al., 2016; McDonnell et al., 2017; Welsby et al., 2019). Notable barriers to accessing these treatment options are limited financial resources for uninsured treatments and geographic distance from rehabilitation treatment centers (Seo et al., 2018). Regardless of the pharmacological, surgical, or accessory therapies utilized for the management of PD, care partners are critical for their access and delivery.

## 2.2 Care Partners and PD

Motor and non-motor symptoms of PD present challenges not only for the PwPD, but also for the involved care partners. Care partners of PwPD may be spouses, adult children, or other close family or friends. Providing care, in this context, may constitute many duties including assistance with activities of daily living, emotional support, and carrying out additional household duties. While care partners for PwPD have diverse profiles, the literature describing experiences of care partners for PwPD most often features participants who are female spouses of the PwPD (Leiknes, Lien, & Severinsson, 2015; Mosley et al., 2017). Consequently, the vast majority of care partner-centric data reports female experiences and not the diversity of this population. Cerri, Mus and Blandini (2019) suggest this discrepancy is not only due to the slight predominance of PD in males, but also due to mortality in men being earlier than in women. Due to earlier male mortality, female PwPD are more often widowed by the time they are in need of care, and the burden of care for female PwPD often falls on their adult children (Cerri et al., 2019). With the aging population, it has been projected that more care partners in the next two decades will be adult children rather than spousal care partners (Cerri et al., 2019). Understanding the experiences of burden among care partners of PwPD is critical for the development of suitable resources and supports. This is especially important considering the limited body of literature that has explored the experiences of diverse groups of care partners of PwPD.

Since the 1960s, researchers across health disciplines have attempted to describe the experiences of those in care partner roles for individuals with diverse health conditions. “Caregiver burden” is a pervasive term found throughout this literature and has evolved into a multidimensional construct describing negative experiences of stress arising from providing care to an individual with a health condition impacting functional ability (Adelman et al., 2014). Grad and Sainsbury (1963) used the term “caregiver burden” to characterize any cost to a family. Hoenig and Hamilton (1966) and then Platt and Hirsch (1981), differentiated between the emotional aspects of providing care and the stressful actions comprising care. Montgomery et al., (1985) further developed such a two-dimensional view of burden by defining activities related to providing care as objective burden and defining the emotional and psychological experience of the care partner as subjective burden. Within the same publication, the authors also presented the Montgomery Caregiver Burden Scale (Montgomery et al., 1985). While this measure was developed through

the study of care partners for “elderly” family members rather than PD or any other specific health condition, it has since been used in studies specific to care partners for PwPD (Kim et al., 2007). Other conceptualizations for subjective burden have since appeared in the literature related the stress associated with the care partner role. For example, Ekberg, Griffith and Foxall (1986) suggested “caretaker role fatigue”, while Skaff and Pearlin (1992) suggested “role engulfment”. The overarching common factor among these studies and conceptualizations of burden is that care partners may experience an imbalance between needs for physical and mental resources to care for the recipient, and resources available within the family unit or community at large.

Zarit, Reever, and Bach-Peterson (1980) considered care environments and resource availability as the most direct influences on care partner well-being and developed a 29-item measure of care partner burden, through studying care partners of people with non-specific dementia. The Zarit Caregiver Burden Inventory (ZBI) reports one global score which is directly proportional to the extent to which burden is experienced. Further studies have categorized the components of the ZBI into either three or five factors of burden. For example, Ankri et al (2005) divided the ZBI into three dimensions: guilt, psychological strain, and social and personal life consequences. In contrast, Vatter, McDonald, and Stanmore (2018) stratified the ZBI into 5 dimensions: social and psychological constraints, personal strain, interference with personal life, concerns about future, and guilt. While there is not a consensus on the specific strata within the ZBI, the measure may be used as a global measure of burden and can be used as a measure of separate facets of burden. Further, the ZBI has been validated for use in the study of care partner experiences specific to caring for PwPD (Martinez-Martin et al., 2007).

It is important to note that not all care partner experiences are negative. Studies have described positive aspects of providing care for PwPD with findings showing increased sense of purpose in care partners’ lives and improved family relationships (Konstam, 2003; Barken, 2014). However, when negative experiences outweigh positive experiences for a care partner, both the care partner and the PwPD may experience significant negative outcomes (such as care partner burden) (Theed et al., 2015, Mosley et al., 2017). Health consequences of care partner burden on the individual include fatigue, weakened physical health and immune function, increased risk of cardiovascular disease, decreased quality of life, and increased mortality (Mosley et al., 2017;

Bhimani, 2014; von Kanel et al., 2008; Kuzuya et al., 2011). Mental health represents a major burden on care partners for PwPD, with 12% to 50% meeting the diagnostic threshold for depressive and anxiety disorders (Mosley et al., 2017). Further, in a Scandinavian 8505-person sample of care partners of PwPD, spousal care partners of PwPD showed greater mortality 5 years after the first PD-related hospitalization for the PwPD, compared to the general population control (Nielsen et al., 2014). This burden affects not only the care partners, but also the PwPD who have been shown to also experience worsened quality of life when a care partner experiences severe burden (Carod-Artal et al., 2013). Furthermore, sustained care partner burden is strongly associated with institutionalization of the PwPD, a widely undesirable outcome in eldercare (McLennon et al., 2010; Abendroth et al., 2011).

Due to the commitment involved with taking on a care partner role for a PwPD, care partners often experience less capacity to engage in their own meaningful activities or even to engage in self-care and maintenance of personal health (Mosley et al., 2017). In a study investigating the psychosocial challenges experienced by care partners, Martin (2015) asserted that feelings of uncertainty for the future, preemptive grief, inability to leave the home, and guilt over an inability to “rescue” the PwPD are common to the subjective experience of care partners for PwPD. These findings echo the results reported by Roland et al (2010), which emphasized the psychological stressor of ensuring the safety of the PwPD leading to a loss of ability to leave the home, as well as the stressor of social isolation resulting from the unpredictability of symptoms. While participants in these types of studies may not be assessed for care partner burden, their common experiences of stress may be reflective of emerging burden in some situations.

### 2.3 Factors Influencing Care Partner Burden and Related Experiences

Care partner burden for PwPD has been established to have three major sources: 1) disease related factors, including those related to symptoms presenting in PwPD, 2) those related to the specific treatments and treatment side-effects experienced by the PwPD, and 3) care partner-related factors, as in those factors which are innate to the care partner and their respective environment.

### 2.3.1 Disease Related Factors

The unique set of symptoms presenting in a PwPD contribute to the specific duties a care partner must undertake and may contribute to changes in the care partner's social realities.

Consequently, the set of symptoms of PD determine the stressors causing the burden a care partner may experience. Neuropsychiatric symptoms (apathy, anxiety disorders, and depressive disorders, psychosis, cognitive impairment and dementia, and impulse control disorders) are consistently reported as the PD symptoms which are most distressing for the care partners and are most associated with care partner burden (Aarsland et al., 1999; Shin et al., 2012; Torny et al., 2018; Chahine et al., 2021).

Anxiety in PwPD is commonly associated with care partner burden. PwPD may experience anxiety as panic disorder, social phobia, generalized anxiety, or subclinical symptoms of tension, irritability, or stress (Morley et al., 2012; Greenwell et al., 2015; Mosley et al., 2017). Often, PwPD begin to engage in avoidant behaviours leading to an unwillingness to leave the home, therefore limiting care partners in their capacity to maintain their social network unless they leave the PwPD alone (Ozdilek & Gunal, 2012; Aarsland et al 2007). For PwPD, supervision by a care partner can be closely associated with the perception of safety; this can increase care partners' feelings of pressure and guilt for wanting or needing time alone or away from the PwPD (Carod-Artal et al., 2013).

Numerous studies link depression and depressive symptoms (such as anhedonia, pessimism, feelings of sadness and guilt, and thoughts of suicide) in PwPD to care partner burden and depressive symptoms in care partners (Aarsland et al., 1999; Schrag et al., 2006; Santos-Garcia & Fuente-Fernandez, 2015; Martinez-Martin et al., 2015; Carod-Artal et al., 2013; Torny et al., 2018). A variety of mechanisms of care partner burden stemming from PD-related depression have been suggested, with specific support from qualitative studies. For example, depression may cause the PwPD to withdraw in many life activities and social circumstances and to reduce warmth and reciprocity in relationships (Martin, 2015). Through a typical decrease in motivation consistent with depression, PwPD experiencing depression may further lose independence, therefore increasing demands of the care partner (Aarsland et al., 2007). Anhedonia, a reduced ability to experience pleasure, experienced by the PwPD may lead to a more negative environment for the care partner (Martin, 2015; Bhimani, 2014). Changes in the care partner-



PwPD relationship resulting from depressive symptoms in PwPD may also cause distress for the care partner, especially in spousal relationships (Thommessen et al., 2002; Martinez-Martin et al., 2007). Considered together, these symptoms contribute to a more burdensome environment for the care partner. The PwPD's expressed feelings of guilt over their increased dependence can also cause the care partner to experience their own guilt for having negative emotions toward the care situation (Shim et al., 2011). Finally, in severe cases of depression in PwPD, wherein self-harm and suicidal thoughts are areas of concern, the safety of the PwPD may preoccupy the care partner and lead to increased anxiety in the care partner (Mosley et al, 2017).

Apathy presents in PwPD as a lack of motivation, emotionality, and empathy, which has been associated with care partner burden in several studies (den Brok et al., 2015; Leroi et al., 2012b). Apathy may result from depression and/or cognitive deficits related to PD, but is also operationalized as an independent symptom, and may exist independently of either depression or cognitive impairment (Leiknes et al., 2010). PwPD displaying apathy may lack warmth in social settings, particularly with their care partners. When studying care partner relationships with PwPD and people with Alzheimer's disease, Martinez et al (2018) found that PwPD experiencing apathy, on average, experienced a decreased ability to detect emotion in their care partner and decreased empathy. Leroi et al (2012b) found that PwPD who are more severely affected will require their care partners to structure their daily routine and may need prompting to complete basic tasks such as washing or brushing of teeth. Further, Leroi et al (2012b) found that burden experienced by care partners, measured by the ZBI, and depression in care partners directly correlated with lower empathy scores and with lower emotion detection scores in the PwPD. Considering these results, the ability, or lack thereof, for a PwPD to understand their care partner's emotions and experiences can decrease the quality of the relationship between the care partner and PwPD, therefore contributing to the experience of care partner burden. Mosley et al., (2017) suggests providing care for a PwPD presenting apathy is particularly taxing, as care partners may feel less appreciated by the PwPD and also feel as though they must continue to be diligent, as the PwPD will not look after themselves if left alone, regardless of functional capacity. Mosley and colleagues (2017) cite Roland, Jenkins and Johnson (2010), a qualitative study that does not mention apathy specifically but identifies psychological stressors in care partners arising from having to manage symptoms when the PwPD cannot manage themselves.

Many studies have also linked cognitive impairment, ranging from mild cognitive impairment to dementia, in PwPD with care partner burden (Aarsland et al., 2007; Martinez-Martin et al., 2015; Lageman et al., 2015). Dementia in PwPD can result from deficits in the domains of attention, language, memory, executive functioning, and visuospatial orientation, while mild cognitive impairment manifest as deficits in these domains in isolation or in combination, to varying degrees (Kehagia et al., 2010). These cognitive changes can lead to great emotional strain in care partners and often contributes to increased dependence and decreased reciprocity in the PwPD-care partner relationship (Lawson et al., 2018; Vatter et al., 2018). Jones et al (2017) established that mild cognitive impairment in PwPD gives rise to an intermediary report of subjective burden, relative to those without cognitive deficits and those with dementia. Kudlicka, Clare and Hindle (2014) analyzed 65 PwPD-care partner dyads to determine that burden experienced by care partners was most significantly correlated to care partner-rated cognitive deficits in the PwPD, as opposed to PwPD self-reported cognitive deficits. As cognitive impairment is multifaceted, some studies have investigated the influence of isolated cognitive deficits on care partner burden. For example, some PwPD lack insight into their executive functional deficits, therefore overestimating their executive functioning (i.e., the cognitive abilities which mediate goal-directed, orderly, and flexible behaviour). Burden is influenced by the degree of disagreement between the care partner and the PwPD on executive functioning (Kudlicka et al., 2014). Raein, Ortiz-Hernandez & Bengtson (2019), in a mixed-methods study of 50 PwPD-care partner dyads, found that PwPD and care partners reported different priorities related to the cognitive impairments which contributed to the reported experience of burden in care partners through the ZBI scores, considered with PwPD reports and through focus group data. Specifically, some overlap in priorities occurred between the groups, when considering the memory item of misplacing objects (Raein et al., 2019). However, PwPD-identified priorities focused on more on language items such as word finding, recent event recall, and name recall, while care partner-identified priorities focused on executive function, attention and fluctuation items such as decision making, motivation to start tasks, focus and thinking ability consistency (Raein et al., 2019).

Care partner burden is also influenced by the presence of psychosis and hallucinations in PwPD (Martinez-Martin et al., 2015). For example, Marsh et al (2004) compared care partners of PwPD with and without psychosis and found psychosis to be significantly influential on care partner

burden measures, when accounting for disease progression and other neuropsychiatric symptoms. A qualitative study of psychosis in PwPD and care partner burden identified that psychotic symptoms can be most distressing due to uncertainty of these symptoms and lack of information about what is “normal”, perceived personality changes in the PwPD, and PwPD suspicion of unwanted behaviours in the care partner, leading to decreased trust in the relationship (Williamson et al., 2008).

Impulse control disorders, such as excessive gambling, binge-eating, compulsive behaviours, and hypersexuality, may be financially problematic and emotionally distressing for care partners (Mosley et al., 2017). Leroi et al (2012a) compared burden in care partners for PwPD experiencing no neuropsychiatric symptoms, PwPD experiencing apathy, and PwPD experiencing impulse control disorders, and found the highest levels of burden in both types of neuropsychiatric symptoms, with no significant differences between the two groups. Mosley et al (2017) suggests that for spousal care partners, relationship quality may suffer if the problematic impulsive behaviour become protected or hidden by the PwPD, specifically when dishonesty about engaging in them is involved. In instances where hypersexuality is associated with pornography use or with extramarital affairs, a care partner may experience a sense of betrayal (Mosley et al., 2017). This can be made worse if the care partner is unaware that these behaviours are associated with PD and if the PwPD does not identify their behaviour as harmful to themselves or those close to them (Mosley et al., 2017).

While motor symptoms are the primary focus in most treatment of PD, these symptoms are not consistently described as influencing the extent to which care partners experience difficulty within the role (Greenwell et al., 2015; Mosley et al., 2017). In a survey-based study, Schrag et al (2006) found that greater care partner burden scores, as measured by the Zarit Burden Inventory, and greater depression scores, as measured by the Beck Depression Inventory, were associated with reports of increased falls and overall disability experienced by PwPD. While Schrag et al (2006) assert that motor symptoms themselves did not influence burden significantly, these symptoms are considered by the authors to be an important contributor to disability and likelihood of falling. Such assertions about the relationship between care partner burden and PwPD-experienced disability as a result of the motor symptoms of PD are supported by subsequent work (Martinez-Martin et al., 2007; Grun et al., 2016), which report repeated

findings that progression through H&Y stages, decided by motor symptoms and disability, correlate to increased burden. Moreover, Roland, Jenkins and Johnson (2010) found that care partners reported an increased anxiety over the PwPD falling. In contrast, other studies (Genç et al., 2019; Torny et al., 2018) have reported that motor symptoms do not impact care partner reports of burden and depression, and have asserted that neuropsychiatric symptoms become increasingly likely with the later H&Y disease stages, thus potentially confounding the findings that suggest a relationship between disability and burden.

Sleep disturbances in PwPD, which can manifest as interrupted sleep with physical pain or akinesia and/or tiredness upon waking up, have also been reported to influence care partner burden (Mosley et al., 2017). Specifically, in spousal care partners sharing a bed with the PwPD, direct links are made between reports of any type of sleep disturbance experienced by PwPD and care partner burden and depression outcomes (Happe & Berger, 2002; Viwattanakulvanid et al., 2014; Bartolomei et al., 2018). Mechanistically, poor sleep has been identified as a causal factor for depression and anxiety in general populations (Alvaro et al., 2013). As such, both the PwPD and the care partner may experience worsening symptoms of depression and anxiety, if sleep disturbances are experienced. While the link between sleep disturbance and burden has been most often discussed in the present literature within spousal relationships involving bed-sharing, some data has suggested a similar relationship between sleep disturbances and care partner burden in care partners who are woken up to assist the PwPD but sleep separately (Mercer, 2015). Speech disturbances have only once been studied in relation to the experiences of care partners for PwPD. Mach et al (2019) conducted a qualitative analysis using semi-structured interviews, with care partners for PwPD specifically about speech impairment. In relation to domains of care partner burden, speech disturbances instilled a sense of grief over loss of communication ability within the care partner-PwPD dyad and therefore a decline in the relationship quality and social environment within the homecare setting (Mach et al., 2019).

### 2.3.2 Treatment Related Factors of Burden

While the symptom profile of PwPD contributes meaningfully to the care environment and influence the duties a care partner will undertake, the treatment process also contributes to this

environment in several ways. Treatment of non-motor symptoms has been found to influence reported care partner burden and will be discussed with interventions for burden in this review.

While disease progression itself is related to increased care partner burden, treatment in later stages of the disease can have differential influences on care partner experiences. In a study of 126 PwPD-care partner dyads, Tessitore et al (2018) found that in advanced stages of PD, changes in pharmacological strategies to improve efficacy of treatment meaningfully improve care partner burden outcomes. However, a fear of change was reported in PwPD who did not want to switch to advanced therapy, potentially causing tension in the care partner-PwPD relationship, and potentially indicating increased nonmotor symptoms. These factors were not considered in the data collection of the study.

In a longitudinal study in Australia on 64 PwPD-care partner dyads, Mosley et al (2018) found that after subthalamic deep brain stimulation treatment, care partners did not experience relief of burden, with no change to care partner burden reported. Soileau et al (2014) found in a six-month time frame after deep brain stimulation, that despite 29% improvement in the MDS-UPDRS motor score, care partner burden index scores do not improve. Overall, both studies suggested that while PwPD experience some symptom relief, and perceive less disability, these changes do not meaningfully influence care partner outcomes, and may cause tension within the care partner-PwPD relationship, due to disagreement between the care partner and PwPD on the PwPD's abilities. Soileau et al (2014) suggest that while PwPD feel the physical changes of the procedure and therefore may perceive more freedom in activities that they can engage in, care partners may be inclined to maintain a certain worry about risk, regardless of changes in symptom severity. Haahr et al (2013) found in a longitudinal interview study, that spousal care partners for PwPD in the first year of deep brain stimulation treatment felt either a renewed sense of freedom or challenge due to change and worry. While no data on care partner burden was collected in this study, those themes of challenge in the face of change, and continued worry support the suggestion that deep brain stimulation is not a treatment for PwPD that can indirectly improve care partner burden.

In qualitative studies, care partners have identified lack of access to information as a significant stressor throughout the process of caring for a PwPD (Tan et al., 2012; McLaughlin et al., 2011; Schrag et al 2004). In early stages of the disease, exclusion of care partners from conversations

surrounding care may contribute to a lack of care partner information and uncertainty over realistic expectations of disease progression (Tan et al., 2012). Care partners have also expressed worry over lack of training in specific physical duties in later stages of disease progression (Goy et al., 2008). Additionally, some care partners have reported feelings of invisibility within the processes that directly influences their lives (Goy et al., 2008; Schrag et al., 2004). Considered broadly, these findings suggest that throughout the treatment of PD, care partner inclusion is necessary within the circle of care, and information about the changes and challenges possible throughout the progression of PD.

### 2.3.3 Care Partner Related Factors of Burden

Factors influencing burden in care partners for PwPD may also be independent of the experience of PD. These include the care partner's social environment, and their intrinsic personal factors.

Greenwall et al (2015) reviewed demographic correlates of burden and found that age and education level were not significant predictors of the experience of subjective burden. Perhaps surprisingly, given the higher proportion of female care partners, gender is not consistently reported to not be a factor for burden, though some studies have reported more subjective burden in female care partners (Calder et al., 1991; Lyons et al., 2009, Greenwall et al., 2015; Mosley et al., 2017). Socioeconomic status, on the other hand, has been established as a mediator for negative care partner outcomes. O'Connor and McCabe (2011) studied the influences of mood and financial status on the quality of life of care partners for people living with neurodegenerative disease, including PD, and found that income and mood were significant predictors for quality of life in care partners for PwPD. Edwards and Scheetz (2002) found that spousal care partners for PwPD living with a household annual income of less than US\$25,000 reported more than double the mean burden score of those in all other income brackets.

Cultural identity influences how specific experiences of burden in care partners may manifest, however there is no evidence of differences between cultural groups in the extent to which care partners for PwPD experience burden (Tanji et al., 2013; Sanyal et al 2015). Tanji and colleagues (2013) compared experiences of care partners for PwPD living in Maryland, USA and Yamagata, Japan and found that care partners in Maryland reported greater emotional stress while care partners in Yamagata reported greater physical experiences of stress. The overall

experience of being overwhelmed by care responsibilities in this study were similar (Tanji et al., 2013).

The psychological characteristics of care partners contribute to appraisal and coping strategies and have been discussed in the context of care partner burden and well-being in PD (Mosley et al., 2017). Mental health challenges in care partners which precede the diagnosis of PD are frequently discussed as a factor, but this is not often directly reported (Martinez-Martin et al., 2008; Mosley et al., 2017). The presence of clinically significant symptoms of anxiety and/or depression are often reported in a cross-sectional capacity only (Mosley et al., 2017). Qualitative study of the care partner experience suggests this relationship as well, but quantitative measures are not present to evaluate burden, anxiety or depression (Goy et al., 2008). Tew et al (2013) tested depression anxiety and the personality traits of conscientiousness, openness to experience, neuroticism, agreeableness, and extraversion to establish personal factors related to quality of life and burden in care partners for PwPD in a cross-sectional study. This study found that the presence of anxiety and depression in care partners was correlated with higher burden and poor quality of life, along with high levels of the personality trait neuroticism. Conversely, they observed that high conscientiousness was correlated to better care partner outcomes (Tew et al., 2013). While this study demonstrates the relationship between care partner depression and anxiety with increased burden, mood disorders preceding PD onset are not discussed. Therefore, no conclusion can be made about whether these care partner traits presented as a result of the care environment, or as a personal factor influencing the way the care partner interprets their environmental stressors. Ma et al (2018) performed a similar study establishing that conscientiousness has a stronger positive influence over psychological quality of life, relative to neuroticism in its negative influence. Another mental trait, dispositional optimism, has been identified as an important protective factor against burden. Lyons and colleagues (2009) identified in a 10-year longitudinal study of spousal care partners of PwPD, that care partners displaying high optimism and relationship quality (referred to by Lyons and colleagues as mutuality), with low pessimism also reported lower burden 10 years into the study.

Specific social abilities are also personal factors of a care partner that may influence burden. While the PwPD experience changes in their abilities to detect emotion in conversational partners, Martinez et al (2018) further found that care partners also significantly varied in their

emotion detection capacity (or the ability to accurately interpret emotions of a conversational partners). Less accurate emotion detection abilities in care partners was correlated with higher care partner burden, independent of the empathy and emotion detection abilities of the care partner. It is proposed that such care partners may lack general social skills, therefore potentially compromising their abilities to maintain positive social relationships within the family and outside of the family (Martinez et al., 2018).

Social supports can help maintain well-being as a care partner and are protective against subjective burden in the context of PwPD (Greenwell et al., 2015; Mosley et al., 2017). Studies of broad factors influencing care partner burden in PD reference the importance of social support, without elaboration from the care partner participants as to how or why this is the case (Schrag et al., 2006; Martinez-Martin et al., 2015; Grun et al 2016). Studies focused specifically on the relationship between social support and care partner burden support these claims. For example, Yang et al (2019) found that care partner self-reporting of strong social support not only directly correlated to lower burden but also to greater care partner self-efficacy. In a qualitative study, Boersma et al (2017) found that care partners consistently perceived a need for emotional support from social networks. Theed, Eccles and Simpson (2016) also qualitatively identified social support as important to care partners as a facilitator for coping. Since families can be an important source of social support, Trapp et al (2018) sought to study the influence of family function and support on burden and in this cross-sectional study found that quality of family function related to care partner satisfaction, moderated by the extent to which burden is perceived. This may be due to the sharing of the burden between family members as well as the support of the family network. Taken together, social support in any capacity can be understood as an important care partner-identified protective factor against burden.

## 2.4 Summary

To summarize, the clinical symptom-focused treatment of PD does not provide significant relief for care partners of PwPD, and in the case of some treatment options, may exacerbate symptoms which are most distressing for care partners. While the treatment of PD should primarily focus on patient needs, the needs of care partners who are integral to the wellbeing of PwPD, must also be addressed. Sustained negative experiences of care partners of PwPD can lead to negative



health consequences for care partners and can negatively impact the care environment for all involved. While there is evidence of many contributing factors to the development of care partner burden, identification of the specific needs and sources of burden of these care partners, with a regional focus that accounts for available community resources and supports, is limited.

This study investigated care partner burden in PD in the Southwestern Ontario region. As discussed, the ever-changing demographic of PD care partners necessitates investigation to specific populations, which will have specific available resources and demographic makeups, especially in a region that has recently experienced a surge in population. Thus, the purpose of this study was to explore the experiences of care partners for PwPD living in Southwestern Ontario and quantitatively describe care partner struggles within the role.

## 3 Methods

This quantitative, cross-sectional, online survey study explored the objective and subjective burden experienced by care partners of PwPD. The study was approved by Western University Health Sciences Research Ethics Board (WREB # 112490). Participants provided informed consent by clicking “I agree to participate” to proceed from the Letter of Information to the beginning the survey. Continued consent was implied through participation.

### 3.1 Participants

Participants were recruited through the following strategies: the email newsletter from the Parkinson’s Society of Southwestern Ontario (PSSO); advertisements on the PSSO website; support groups for people with Parkinson’s disease and their care partners; and at regional workshops carried out by PSSO. Participants were included if they: (1) were fluent in English (the language of the survey); (2) provided care for someone living with Parkinson’s disease within Southwestern Ontario at the time of completing the survey; (3) were able to complete the survey online. The boundaries of Southwestern Ontario used in this study were those of the PSSO (full inclusion of the following counties: Essex, Chatham-Kent, Lambton, Elgin, Middlesex, Huron, Perth, Bruce, Grey, Oxford, Waterloo, Dufferin, Brant, Norfolk and Haldimand; inclusion of Wellington County, west of Highway 18). Participants were excluded if they cared for a PwPD who lives outside of the defined region.

### 3.2 Outcome Measures

The survey was delivered via Qualtrics, a secure online survey platform. Qualtrics is General Data Protection Regulation (GDPR) compliant and all data collected via Western’s Institutional License is stored in an Irish server (Voigt & von dem Bussche 2017). The survey consisted of a demographic section and three standardized outcome measures totaling 108 items: the Zarit Burden Inventory (ZBI) (Zarit et al., 1987; Zarit et al., 1980), the Montgomery Borgatta Burden Scale (MBBS) (Montgomery et al., 2000) and Parkinson’s Disease Questionnaire – Carer (PDQ-Carer) (Jenkinson et al., 2012). Data was collected between April and December of 2019.

### 3.2.1 Demographic Questionnaire

This section collected data on the age, gender, marital status, employment status, level of education, and income status of the care partners. Data pertaining to the relationship between the participant and the PwPD was also collected, including proximity between PwPD and care partner residences, length of time (in years) spent providing care, and the nature of the relationship between the care partner and the PwPD. Collected data about the PwPD included age, gender, and number of years since diagnosis.

#### 3.2.1.1 Activities of Daily Living

The amount of assistance care partners provide the PwPD with activities of daily living (ADL) was assessed with a Likert-scale, where care partners indicated for each ADL if they provide the PwPD with “no assistance”, “some assistance”, or “complete assistance”. These responses were then assigned a score of 1 for “no assistance”, 2 for “some assistance” and 3 for “complete assistance”. Care recipient independence in basic ADLs was measured with the Katz ADL index (Katz et al., 1970). Basic ADLs are activities necessary to independently care for one’s physical needs (Edemekong et al., 2020) such as bathing, or toileting. Care recipient independence in instrumental ADLs was assessed through the Lawton’s IADL scale (Lawton & Brody, 1969). Instrumental ADLs are activities necessary to independently manage oneself in the community (Edemekong et al., 2020), and include activities such as laundry, or cooking. Scores were generated according to Cromwell, Eagar and Poulos (2003). Each response from the Katz ADL and Lawton’s IADL scales was assigned a score of 1-3, 1-4 or 1-5, depending on the number of possible responses that are available for each item of the scale. A higher score indicated lower functional independence.

#### 3.2.2 Care Partner Burden

Two measures were used to assess care partner burden: 1) the Zarit Burden Inventory (ZBI) (Zarit et al., 1987; Zarit et al., 1980) and 2) the Montgomery Borgatta Burden Scale (MBBS) (Montgomery et al., 2000). These measures can be used to assess the multidimensional nature of care partner burden (Ankri et al., 2005; Lau et al., 2015; Savundranayagam and Montgomery, 2010). The 22-item ZBI is commonly used in the study of burden in care partners for PwPD and reports burden as a singular overall score (global score).

Responses are recorded on a Likert-scale ranging from “never” to “nearly always”.

Corresponding numeric scores between zero and four were assigned, where responses indicating higher frequency correspond to higher numeric scores. Global scores of 0-20 indicate little to no burden, 21-40 indicate mild-to-moderate burden, 41-60 indicate moderate-to-severe burden, and 61-88 indicates severe burden (Zarit et al., 1987). Since this measure has been used widely in studies involving care partners for PwPD (Mosley et al., 2017), its use in this study allows for easier comparison of the presently studied population to comparable populations in other geographic regions.

The Montgomery Borgatta Burden Scale (MBBS) has not been used as frequently in the study of care partners for PwPD as the ZBI. It has, however, been used in studies of care partner experiences to report on the objective and subjective dimensions of burden experienced by those giving informal care to people with dementia and various neurodegenerative disorders (Montgomery et al., 2000; Savundranayagam and Montgomery, 2010). The measure was included in this study to address the multidimensional nature of care partner burden as a construct. The MBBS further divides the subjective dimension of burden into subjective relationship burden, the negative impact the care role has on the relationship between care partners and care recipients, and subjective stress burden, the experience of emotional stress or anxiety due to providing care. All items in the MBBS are reported on a Likert scale, with answer options including “not at all”, “a little”, “moderately”, “a lot”, “a great deal”. For each item of the three dimensions of burden in this measure, a score of 1 to 5 is ascribed to each item. A higher number indicates higher strain.

In the MBBS, objective burden is determined by six items. These items include 1) infringement on time a care partner has for themselves, 2) infringement on available time for other family and friends, 3) infringement on available time to attend to personal work and chores, 4) infringement on ability to go on vacations or trips, 5) infringement on available time to participate in recreational activities, and 6) infringement on personal privacy. Possible objective burden scores using this measure range from 6 to 30. Subjective relationship burden is determined by five items. These items include: 1) unreasonable requests made of the care partner by the dependent relative, 2) demands over and above the needs of the dependent relative, 3) perception of being taken advantage of by the dependent relative, and 4) attempts of manipulation by the

dependent relative, and 5) conflict between the care partner and dependent relative. Possible scores of subjective relationship burden, using this measure, range from 5 to 25. Subjective stress burden is also determined with five items. These items include 1) nervousness caused by providing care, 2) depression caused by providing care, 3) feelings of hopelessness caused by providing care, 4) anxiousness caused by providing care, and 5) worry caused by providing care. Possible scores of subjective stress burden range between 5 and 25.

The inclusion of both care partner burden measures increased the robustness of data. Since care partner burden is not a universally standardized construct, the inclusion of both measures offers a broader ability to interpret data related to burden. Both measures have been used in both research and clinical settings to evaluate experiences of burden (Lau et al., 2015; Savundranayagam & Montgomery, 2010).

### 3.2.3 Quality of Life

The Parkinson's Disease Questionnaire – Carer (PDQ-Carer) was used to assess care partner subjective quality of life (Jenkinson et al., 2012). This tool reports on four connected dimensions of quality of life, specific to the experiences of care partners for PwPD. Twelve items address social and personal activities, six items address anxiety and depression, six items address stress, and five items address self-care. Item scores are generated by converting item responses of “Never” to 0, “Occasionally” to 1, “Sometimes” to 2, “Often” to 3, and “Always” to 4. The scores for each dimension are calculated by dividing the sum of the individual item scores by the maximum possible sum for each dimension and multiplying this number by 100. Jenkinson et al (2012) identify a score of 60 or higher as indicating severely compromised quality of life. As a related construct to burden (Conrad et al., 2018; Farina et al., 2017), the inclusion of a quality of life measure encapsulates a broader description of the experiences of the participants in this study.

## 3. 3 Data Analysis

First, descriptive statistics were generated for the entire sample. Then, data were stratified into groups based on the clinical categories recommended for interpreting ZBI scores (little to no burden: 0-20, mild to moderate: 21-40, moderate to severe: 41-60, severe: 61-88) (Zarit & Zarit

1987). Descriptive statistics were generated for these groups. Normality was assessed with the Shapiro-Wilk Normality test. Due to the non-parametric nature of these data, significant differences between groups were assessed using the Kruskal-Wallis test and Dunn's post-hoc test with  $p$  values adjusted with the Bonferroni method (Kruskal & Wallis 1952, Dunn 1964). Dunn's post hoc tests were applied when Kruskal-Wallis test results indicated significant differences in the data, with an adjusted alpha of 0.025. This statistical approach allows for testing ordinal data (Kruskal & Wallis 1952).

### 3.3.1 Missing Data

Pairwise deletion was used in the stratified analysis of this study, to handle missing items from the demographic and ADL measures, and to handle instances where participants had a ZBI score, but not a PDQ-Carer score or a score for specific MBBS dimensions. Due to the nature of the analysis, a ZBI score was necessary for inclusion into a group.

For missing outcome measures item, the strategy set out by the authors of the MBBS was used and adjusted to fit the number of items of PDQ-Carer and ZBI (Montgomery et al., 2000). This strategy sets out a maximum number of item answers for a dimension which can be missed in order to generate a score for that dimension. For the MBBS, each dimension may have a maximum of two missing items. This maximum was adjusted to eight missing items for ZBI responses. For the PDQ-Carer, the maximum for personal and social activities domain was four missing items, while a maximum of two missing items was acceptable for the remaining domains. When the number of missing items did not exceed the maximum, scores were calculated by dividing the raw score by the highest possible score based on the number of completed items, then multiplying that quotient by the highest possible score for the dimension (Montgomery et al., 2000).

## 4 Results

### 4.1 Sample Characteristics

A total of 46 people agreed to participate in this study. Eight of these care partners did not meet inclusion criteria and were excluded due to: their geographic location falling outside of Southwestern Ontario (n=5), the omission of a confirmed Southwestern Ontario postal code (n=1), or self identification as being a paid personal service worker for the care recipient (n=2). Table 1 summarizes the demographic characteristics for the 38 care partners who met study inclusion criteria. On average, care partners were  $65.4 \pm 14.3$  years old and care recipients were  $72.7 \pm 11.5$  years old. 29 (76.3%) of the care partners in this sample were female, 22 of whom were providing care to their male spouse (75.9% of female sub-sample). Other female care partners in this sample were daughters (n=4; 13.8% of female sub-sample), daughters in-law (n=2; 6.9% of female sub-sample) and mothers to their care recipients (n=1; 3.4% of female sub-sample). Of the nine male care partners in this sample (23.7%), eight (88.9% of the male sub-sample) were providing care to their female spouses. One male care partner provided care to a male friend. Most care partners (n=30; 79.0%) in this sample lived in the same household as the person in their care, with seven care partners (18.4%) indicating that the care recipient resided in a senior housing facility (nursing home, lodge facility, long term care home, etc.), and one care partner indicating their care recipient lives alone (2.6%). Mean disease duration for care recipients across the sample was  $10.1 \pm 7.9$  years, while the mean number of years respondents considered themselves to be in a care partner role was  $8.1 \pm 6.6$  years. Care partners in this sample reported a mean of  $48.4 \pm 57.3$  hours per week spent on caring for their care recipient, with a mean of  $6.5 \pm 16.1$  hours of formal help accessed weekly and a mean of  $6.6 \pm 20.2$  hours of informal help accessed weekly.

**Table 1.** *Demographic Characteristics of the Sample.*

Gender and Relationship to Care Recipient	% of sample	n
Female Care Partners	76.32	29
<i>Spouses</i>	57.89	22
<i>Other relationships</i>	18.42	7
Male Care Partners	23.68	9
<i>Spouses</i>	21.05	8
<i>Other relationships</i>	2.63	1

Living Proximity to Care Recipient	% of sample	n
Living with the Care Recipient	81.58	31
1-10 km	10.53	4
11-25 km	2.63	1
25-50 km	2.63	1
100+ km	2.63	1
Care Recipient Living Circumstances	% of sample	n
Living alone	2.63	1
Living with Family	78.94	30
Long Term Care, Assisted Living, etc.	18.42	7
Annual Care Partner Household Income	% of sample	n
Under \$25,000	5.26	2
\$25,000 to \$49,999	5.26	2
\$50,000 to \$74,999	34.21	13
\$75,000 to \$99,999	28.95	11
\$100,000 +	15.79	6
Not disclosed	10.53	4
Care Partner Employment Status	% of sample	n
Working Full Time	18.42	7
Working Part Time	13.16	5
Retired	60.52	23
Stay at Home, no pay	7.89	3
Care Partner Education Level	% of sample	n
Less than High School	5.26	2
High School	10.53	4
College Diploma	28.95	11
Bachelor's Degree	36.84	14
Graduate Degree	15.79	6
Professional Degree	2.63	1
Access to Assistance	% of sample	n
No Formal or Informal Help	34.21	13
Accessing Formal Help Only	21.05	8
Accessing Informal Help	18.42	7
Access Both Formal and Informal Help	26.32	10



Seventeen care partners (44.7%) reported that they receive informal assistance from family members or friends to help care for the PwPD. Similarly, 18 care partners (47.4%) reported that they receive support from formal service providers. Ten care partners (26.3%) reported receiving assistance from both informal and formal supports. Of those care partners who reported receiving informal support, family and friends assisted with the following activities of daily living and instrumental activities of daily living: shopping (n=8); driving (n=7); transferring (n=7); managing medications (n=5); dressing (n=4); eating (n=4); cooking (n=4); using the phone (n=4); housework (n=4); laundry (n=4); managing finances (n=4); grooming (n=3); toileting (n=3); walking (n=3); climbing stairs (n=2); bathing (n=1); and oral care (n=1). Other informal support received also included: visiting/spending time with the care recipient (n=4); emotional support (n=2); and accompanying the PwPD on outings (n=1). Formal supports accessed by care partners were provided by personal support workers (n=4), retirement residences (n=3), private landscape companies (n=2), and long-term care facilities (n=1). Services provided include bathing, transferring, dressing, housekeeping, meal preparation, medication management, and outside maintenance including lawn care and snow removal.

Care partner assistance provided for ADLs is summarized in Table 2. Instrumental activities of daily living which care partners most often assisted with in this sample include laundry (44.7% provide complete assistance), driving (44.7% provide complete assistance), management of finances (34.2% provide complete assistance), management of medication (34.2% provide complete assistance), and cooking (31.6% provide complete assistance). Care partners most often provided some assistance to their care recipients for grooming (50.0% provide some assistance), housework (34.2% provide some assistance), managing medications (34.2% provide some assistance), and shopping (31.6% provide some assistance). Care partners in this sample least often assisted with oral care (73.7% care partners provide no assistance), bathing (52.6% provide no assistance), toileting (57.9% provide no assistance) and telephone use (52.6% provide no assistance).

**Table 2.** *Care Partner Assistance Provided to Care Recipient for Activities of Daily Living*

Activity of Daily Living	No Assistance	Some Assistance	Complete Assistance	No Response
Bathing	20 (52.63)	11 (28.95)	2 (5.26)	5 (13.16)
Dressing	11 (28.95)	21 (55.26)	4 (10.53)	2 (5.26)

Activity of Daily Living	No Assistance	Some Assistance	Complete Assistance	No Response
Grooming	16 (42.11)	19 (50.00)	3 (7.89)	0 (0.00)
Oral Care	28 (73.68)	7 (21.05)	3 (7.89)	0 (0.00)
Toileting	22 (57.89)	11 (28.95)	3 (7.89)	2 (5.26)
Transferring	16 (42.11)	17 (44.74)	3 (7.89)	2 (5.26)
Walking	14 (36.84)	16 (42.11)	1 (2.63)	7 (18.42)
Climbing Stairs	17 (44.74)	11 (28.95)	1 (2.63)	9 (23.68)
Eating	19 (50.00)	16 (42.11)	2 (5.26)	1 (2.63)
Shopping	8 (21.05)	12 (31.58)	10 (26.32)	8 (21.05)
Cooking	3 (7.89)	11 (28.95)	12 (31.58)	12 (31.58)
Managing Medications	9 (23.68)	13 (34.21)	13 (34.21)	3 (7.89)
Using the Phone	20 (52.63)	13 (34.21)	2 (5.26)	3 (7.89)
Housework	4 (10.53)	13 (34.21)	12 (31.58)	9 (23.68)
Laundry	9 (23.68)	5 (13.16)	17 (44.74)	7 (18.42)
Driving	7 (18.42)	5 (13.16)	17 (44.74)	9 (23.68)
Managing Finances	8 (21.05)	11 (28.95)	13 (34.21)	6 (15.79)

Note. Table reports number of participants, with percentage of overall sample in parentheses.

Across this sample, care partners reported more care recipient dependence in instrumental ADLs and more independence in basic ADLs (summarized in Table 3). Mode responses across the sample indicated the highest level of dependence possible for laundry, food preparation, and transportation. Mode responses across the sample indicated the most independence possible across all basic ADLs. However, continence, an item with only two options was more evenly split, with 52.6% of care recipients exercising complete control over urination and defecation and 44.7% of care recipients being partially or totally incontinent.

**Table 3.** Care Recipient Level of Functioning Reported by Care Partner.

Activity of Daily Living	Level of Care Recipient Functioning			
Telephone Use	<i>Operates telephone on own initiative, looks up and dials numbers</i>	<i>Dials a few well-known numbers</i>	<i>Answers telephone, but does not dial</i>	<i>Does not use telephone at all</i>
	16 (42.11%)	11 (28.95%)	6 (15.79%)	5 (13.16%)
Shopping	<i>Takes care of all shopping needs independently</i>	<i>Shops independently for small purchases</i>	<i>Needs to be accompanied on any shopping trip</i>	<i>Completely unable to shop</i>
	3 (7.89%)	10 (26.32%)	16 (42.11%)	9 (23.68%)

Activity of Daily Living	Level of Care Recipient Functioning				
Food Preparation	<i>Plans, prepares, and serves adequate meals independently</i>	<i>Prepares adequate meals if supplied with ingredients</i>	<i>Heats and serves prepared meals or prepares meals, does not maintain adequate diet</i>	<i>Needs to have meals prepared and served</i>	
	4 (10.53%)	9 (23.68%)	3 (7.89%)	22 (57.89%)	
Housekeeping	<i>Maintains house alone with occasional assistance (heavy work)</i>	<i>Performs light daily tasks such as dishwashing, bed making</i>	<i>Performs light daily tasks, cannot maintain acceptable level of cleanliness</i>	<i>Needs help with all home maintenance tasks</i>	<i>Does not participate in any housekeeping tasks</i>
	3 (7.89%)	13 (34.21%)	5 (13.16%)	2 (5.26%)	15 (39.47%)
<sup>a</sup> Laundry	<i>Does personal laundry completely</i>	<i>Launders small items, rinses socks, etc.</i>	<i>All laundry must be done by others</i>		
	9 (23.68%)	3 (7.89%)	24 (63.16%)		
Transportation	<i>Travels independently on public transportation or drives own car</i>	<i>Arranges own travel via taxi, does not otherwise use public transportation</i>	<i>Travels on public transportation when assisted or accompanied by another</i>	<i>Travel limited to taxi or automobile with assistance of another</i>	<i>Does not travel at all</i>
	12 (31.58%)	1 (2.63%)	2 (5.26%)	20 (52.63%)	3 (7.89%)
Medication Management	<i>Is responsible for taking medication in correct dosages at correct time</i>	<i>Takes responsibility if medication is prepared in advance in separate dosages</i>		<i>Is not capable of dispensing own medication</i>	
	14 (36.84%)	7 (18.42%)		17 (44.37%)	
<sup>b</sup> Handling Finances	<i>Manages financial matters independently (budgets, writes checks, pays rent and bills, goes to bank); collects and keeps track of income</i>	<i>Manages day-to-day purchases, needs help with banking, major purchases, etc</i>		<i>Incapable of handling money</i>	
	10 (26.32%)	14 (36.84%)		19 (50.00%)	

Activity of Daily Living	Level of Care Recipient Functioning		
Bathing	<i>Bathes self completely or needs help in bathing only a single part of the body such as the back, genital area or disabled extremity</i>	<i>Needs help with bathing more than one part of the body, getting in or out of the tub or shower</i>	<i>Requires total bathing</i>
	21 (55.26%)	8 (21.05%)	9 (23.68%)
Dressing	<i>Gets clothes from closets and drawers and puts on clothes and outer garments complete with fasteners. May have help tying shoes</i>	<i>Needs help with dressing self</i>	<i>Needs to be completely dressed</i>
	21 (55.26%)	10 (26.32%)	7 (18.42%)
Toileting	<i>Goes to toilet, gets on and off, arranges clothes, cleans genital area without help</i>	<i>Needs help transferring to the toilet, cleaning self or uses bedpan or commode</i>	
	29 (76.32%)		9 (23.68%)
Transferring	<i>Moves in and out of bed or chair unassisted. Mechanical transferring aides are acceptable</i>	<i>Needs help in moving from bed to chair</i>	<i>Requires a complete transfer</i>
	28 (73.68%)	10 (26.32%)	0 (0.00%)
<sup>b</sup> Continenence	<i>Exercises complete self control over urination and defecation</i>	<i>Is partially or totally incontinent of bowel or bladder</i>	
	20 (52.63%)		17 (44.74%)
Feeding	<i>Gets food from plate into mouth without help. Preparation of food may be done by another person</i>	<i>Needs partial or total help with feeding or requires parenteral feeding</i>	
	31 (81.58%)		7 (18.42%)

Note. Table reports number of participants who indicated each response, with percentage of sample in parentheses. <sup>a</sup> represents n = 36, <sup>b</sup> represents n=37.

Thirty-six care partners completed the PDQ-Carer. The mean personal and social activities domain score was  $46.8 \pm 26.4$ ; the mean anxiety and depression domain score was  $50.7 \pm 20.7$ ; the mean self care domain score was  $36.1 \pm 26.5$ ; and the mean strain domain score was  $46.9 \pm 21.6$ . Twelve of the care partners (33.3%), received scores above 60 indicating significant compromised quality of life in each of the following domains: personal and social activities; anxiety and depression; and strain. Eight care providers (22.2%) also received scores above 60 in

the self care dimension. Interestingly, 17 care partners (47.2%) received a score of 60 or higher in at least one dimension, with five care partners (13.9%) scoring 60 or higher in all four dimensions. Summary quality of life and burden data are presented in Table 4.

**Table 4.** *Summary of Care Partner Burden and Quality of Life Outcomes*

Outcome	Score Mean $\pm$ SD	
<sup>a</sup> PDQ-Carer		
Personal and Social Activities	46.82 $\pm$ 26.44	
Anxiety and Depression	50.69 $\pm$ 20.71	
Self Care	36.11 $\pm$ 26.54	
Strain	46.88 $\pm$ 21.56	
MBBS		
<sup>b</sup> Objective	16.46 $\pm$ 6.84	
<sup>b</sup> Relationship	9.14 $\pm$ 5.02	
<sup>c</sup> Stress	12.91 $\pm$ 4.90	
<sup>b</sup> Global Score	38.37 $\pm$ 15.09	
<sup>b</sup> ZBI	36.37 $\pm$ 17.59	
<sup>b</sup> ZBI Groups	n	% of sample
Little to No Burden	8	22.86
Mild to Moderate Burden	15	42.86
Moderate to Severe Burden	8	22.86
Severe burden	4	11.43

Note. SD= standard deviation. ZBI = Zarit Burden Inventory; MBBS = Montgomery Borgatta Burden Scale; PDQ-Carer = Parkinson's Disease Questionnaire-Carer. <sup>a</sup> represents n = 36, <sup>b</sup> represents n = 35, <sup>c</sup> represents n = 34.

Thirty-five care partners fully completed the Montgomery Borgatta Burden Scale (MBBS). One additional care partner did not fully complete all items in the stress dimension to generate a specific stress dimensional score, however sufficient data were available to generate a global score. The mean objective burden score was 16.5  $\pm$  6.8; mean relationship burden score was 9.1  $\pm$  5.0; mean stress burden score was 12.9  $\pm$  4.9, and mean global score was 38.37  $\pm$  15.09. Summary data are presented in Table 4.

Thirty-five care partners fully completed the ZBI. Four (11.4%) scored in the severe burden range (61-88), 8 (22.9%) scored in the moderate to severe burden range (41-60), 15 (42.9%) scored in the mild to moderate burden range (21-40), and the remaining 8 (22.9%) scored in the little to no burden range (0-20). Summary data described in Table 4. Additionally, male care partners in this sample reported significantly higher ZBI scores ( $p = 0.001$ ), with a mean of 42.4

compared to the mean ZBI score for female care partners of 34.9, using the Mann-Whitney-Wilcoxon test (Mann & Whitney, 1947; Wilcoxon, 1992).

#### 4. 2 Stratified Analysis

To explore patterns across groups with different experiences of care partner burden, care partners were stratified into four groups based on their ZBI scores: **Little to No Burden** (n=8), **Mild Burden** (n=15), **Moderate Burden** (n=8), and **Severe Burden** (n=4). Comparative demographic across the four groups are summarized in Table 5. There were no significant differences across groups in the demographic data collected, based on ZBI group.

**Table 5.** Summary of Care Partner Demographic Information, Stratified by Zarit Burden Inventory Outcome Groups

	Little to No Burden	Mild Burden	Moderate Burden	Severe Burden	<i>p</i> value (Kruskal Wallis)
Care Partner Age	68.25 ± 12.96	64.13 ± 15.08	64.12 ± 18.17	69.00 ± 14.35	0.97
Care Recipient Age	71.62 ± 11.86	71.13 ± 13.85	74.62 ± 8.90	74.50 ± 10.02	0.96
Years in Care Role	<sup>a</sup> 8.17 ± 6.74	10.56 ± 7.97	4.62 ± 3.75	8.56 ± 4.45	0.22
Disease Duration (years)	8.41 ± 6.60	12.65 ± 9.11	7.24 ± 7.69	9.81 ± 4.18	0.49
Gender and Relationship to Care Recipient	Little to No Burden	Mild Burden	Moderate Burden	Severe Burden	<sup>b</sup> <i>p</i> = 0.69
Female Care Partners	7	12	5	3	
<i>Spouses</i>	6	8	3	3	
<i>Other</i>	1	4	2	0	
Male Care Partners	1	3	3	1	
<i>Spouses</i>	1	3	3	1	
<i>Other</i>	0	0	0	0	

Living Proximity to Care Recipient	Little to No Burden	Mild Burden	Moderate Burden	Severe Burden	$p = 0.61$
Living with the Care Recipient	7	11	6	4	
1-10 km	1	2	1	0	
11-25 km	0	1	0	0	
25-50 km	0	0	1	0	
100+ km	0	1	0	0	
Care Recipient Living Circumstances	Little to No Burden	Mild Burden	Moderate Burden	Severe Burden	<sup>b</sup> $p = 0.82$
Living alone	0	1	0	0	
Living with Family	7	11	6	4	
Long Term Care, Assisted Living, etc.	1	3	2	0	
Annual Care Partner Household Income	Little to No Burden	Mild Burden	Moderate Burden	Severe Burden	$p = 0.87$
Under \$25,000	0	0	0	0	
\$25,000 to \$49,999	1	0	0	1	
\$50,000 to \$74,999	4	5	4	1	
\$75,000 to \$99,999	1	4	1	2	
\$100,000 +	1	3	2	0	
Not disclosed	1	2	1	0	
Care Partner Employment Status	Little to No Burden	Mild Burden	Moderate Burden	Severe Burden	$p = 0.41$
Working Full Time	0	4	3	0	
Working Part Time	2	1	1	0	

Care Partner Employment Status	Little to No Burden	Mild Burden	Moderate Burden	Severe Burden	
Retired	5	9	4	4	
Stay at Home, no pay	1	1	0	0	
Care Partner Education Level	Little to No Burden	Mild Burden	Moderate Burden	Severe Burden	<i>p</i> = 0.58
Less than High School	0	0	1	0	
High School	1	1	0	1	
College Diploma	3	3	5	0	
Bachelor's Degree	4	6	1	2	
Graduate Degree	0	4	1	1	
Professional Degree	0	0	0	0	

Note. Care partner age, care recipient age, years in the care role and disease duration are reported by mean  $\pm$  standard deviation. All subsequent items in this table are reported by number of participants. <sup>a</sup> refers to  $n = 6$ , <sup>b</sup> refers to  $p$  values derived from Chi-square tests for independence.

Severe Burden: A ZBI score between 61-88 was the primary criterion for group membership in this category. All members of this group (three females, one male) were spouses of and lived with their care recipient. Care partners in this group all indicated that they receive formal care assistance, with two of the four care partners in this group also receiving informal care assistance (detailed in Table 6). This is the only group in which all members receive some form of care assistance. Notably, all care partners in this group provided at least some assistance with most ADLs (detailed in Table 7). Care partners in this group provided significantly more assistance (when compared to the Little to No Burden group) to their care recipients in the following basic ADLs: bathing ( $p = 0.0076$ ), dressing ( $p = 0.0099$ ), toileting ( $p = 0.0007$ ), eating ( $p = 0.0037$ ). Further, significant differences between this group and the Mild Burden group were also observed for the amount of assistance provided with bathing ( $p = 0.0098$ ) and toileting ( $p = 0.0218$ ). Differences across care partner assistance with instrumental ADLs were not significant



between the Severe Burden group and any other group, but care partners in this group mostly provided at least some support. The care recipient's level of independent functioning as reported by the care partners in this group was significantly lower than that of the Little to No Burden group in the following instrumental ADLs: Telephone Use ( $p = 0.0237$ ), Housekeeping ( $p = 0.0078$ ), handling finances ( $p = 0.0097$ ); and in the following basic ADLs: bathing ( $p = 0.0164$ ) and dressing ( $p = 0.003$ ) (detailed in Table 8). The care partner-reported care recipients' level of independent functioning was only significantly lower in the Severe Burden group when compared with the Mild Burden group in dressing ( $p = 0.0197$ ). Expectedly, this group held the highest scores across dimensions of the PDQ-Carer and the MBBS (detailed in Table 9). These scores were all significantly higher than those of the Little to No Burden group (Personal and Social Activities,  $p = 0.001$ ; Anxiety and Depression,  $p = 0.0022$ ; Self Care,  $p = 0.0004$ ; Strain,  $p = 0.0006$ ; MBBS-Objective,  $p = 0.001$ ; MBBS- Relationship,  $p = 0.0045$ ; MBBS- Stress,  $p = 0.0006$ ). When compared to the Mild Burden group, scores for the Severe Burden group were significantly higher across all MBBS dimensions (MBBS-Objective,  $p = 0.0063$ ; MBBS- Relationship,  $p = 0.0116$ ; MBBS- Stress,  $p = 0.0115$ ) and the Personal and Social Activities dimension of the PDQ-Carer ( $p = 0.0114$ ). Additionally, every PDQ-Carer score in this group across dimensions was higher than the threshold for seriously compromised quality of life (60.0).

**Table 6.** Care Partner Access to Assistance and Weekly Time Commitment to Care Duties, Stratified by Zarit Burden Inventory Outcome Groups

Access to Assistance	Little to No Burden	Mild Burden	Moderate Burden	Severe Burden	$p$ value (Kruskal Wallis)	$p$ value (Dunn's Test)
No Formal or Informal Assistance	4	4	2	0		
Accessing Formal Assistance Only	2	3	1	2		
Accessing Informal Assistance Only	1	3	3	0		

Access to Assistance	Little to No Burden	Mild Burden	Moderate Burden	Severe Burden	<i>p</i> value (Kruskal Wallis)	<i>p</i> value (Dunn's Test)
Access Both Formal and Informal Assistance	1	5	2	2		
Weekly Hours of Informal Help	0.62 ± 1.77	14.96 ± 31.87	3.62 ± 5.34	2.00 ± 2.45	0.25	
Weekly Hours of Formal Help	1.57 ± 3.74 *	3.65 ± 5.09	2.31 ± 4.85 °	41.75 ± 33.65 * °	0.01	*0.0079 ° 0.016
Weekly Hours Providing Care	59.5 ± 84.18	36.71 ± 44.78	69.00 ± 56.70	50.00 ± 66.75	0.38	

Weekly hours of informal help, weekly hours of formal help, and weekly hours of providing care are all reported as mean ± standard deviation. All other items in this table are reported by number of participants. \* represents significant differences between the Little to No Burden group and the Severe Burden group, ° represents significant differences between the Moderate Burden group and Severe Burden group.

**Table 7.** Care Partner Assistance Given for Activities of Daily Living, Stratified by Zarit Burden Inventory Outcome Groups

Care Partner ADL Assistance Given	Little to No Burden	Mild Burden	Moderate Burden	Severe Burden	<i>p</i> value (Kruskal Wallis)	<i>p</i> value (Dunn's Test)
Bathing	7,1,0,0 *	9,3,0,3 †	2,5,0,1	0,2,2,0 * †	0.00	* 0.0076 † 0.0098
Dressing	3,4,1,0 *	6,8,0,1	1,6,0,1	0,1,3,0 *	0.04	* 0.0099
Grooming	5,2,1,0	5,10,0,0	5,3,0,0	1,1,2,0	0.41	
Oral Care	7,0,1,0	12,3,0,0	5,3,0,0	1,1,2,0	0.05	
Toileting	7,0,0,1 *	8,6,0,1 †	4,4,0,0	0,1,3,0* †	0.00	* 0.0007 † 0.0218
Transferring	5,3,0,0	8,4,1,2	1,6,1,0	0,3,1,0	0.05	
Walking	4,4,0,0	6,6,0,3	5,2,0,1	0,1,1,2	0.15	

Care partner ADL Assistance Given	Little to No Burden	Mild Burden	Moderate Burden	Severe Burden	<i>p</i> value (Kruskal Wallis)	<i>p</i> value (Dunn's Test)
Climbing Stairs	5,2,0,1	8,4,0,3	5,2,0,1	0,0,1,3	0.09	
Eating	7,1,0,0 *	8,6,0,1	4,4,0,0	0,2,2,0 *	0.01	* 0.0037
Shopping	2,4,1,1	3,5,2,5	1,2,4,1	0,0,3,1	0.05	
Cooking	2,3,2,1	1,4,4,6	0,2,4,2	0,0,2,2	0.23	
Managing Medications	2,3,2,1	6,3,5,1	0,5,3,0	0,0,3,1	0.17	
Using the Phone	6,1,1,0	7,7,0,1	4,3,0,1	1,1,1,1	0.70	
Housework	1,4,2,1	0,5,5,5	1,2,3,2	0,1,2,1	0.15	
Laundry	3,1,3,1	2,3,7,3	2,0,4,2	0,0,3,1	0.16	
Driving	3,0,4,1	2,4,6,3	1,0,4,3	0,0,2,2	0.61	
Managing Finances	3,3,1,1	4,5,4,2	0,1,5,2	0,0,3,1	0.02	

Note. Items are reported by number of participants, in the following order: no assistance, some assistance, complete assistance, no response. \* represents significant differences between the Little to No Burden group and the Severe Burden group, † represents significant differences between the Mild Burden group and the Severe Burden group.

**Table 8.** Care Recipient Level of Independent Functioning, Stratified by Care Partner Zarit Burden Inventory Outcome Groups

Care recipient Level of Independent Functioning	Little to No Burden	Mild Burden	Moderate Burden	Severe Burden	<i>p</i> value (Kruskal Wallis)	<i>p</i> value (Dunn's Test)
Telephone Use (1-4)	1.38 ± 0.74 *	1.80 ± 0.94	2.38 ± 0.92	3.25 ± 0.96 *	0.04	* 0.0237
Shopping (1-4)	2.50 ± 0.93	2.60 ± 0.74	3.25 ± 0.71	3.75 ± 0.50	0.06	
Food Preparation (1- 4)	2.33 ± 1.53	2.38 ± 1.41	3.50 ± 0.93	4.00 ± 0.00	0.10	

Care recipient Level of Independent Functioning	Little to No Burden	Mild Burden	Moderate Burden	Severe Burden	<i>p</i> value (Kruskal Wallis)	<i>p</i> value (Dunn's Test)
Housekeeping (1-5)	2.12 ± 1.25 *	3.33 ± 1.35	4.00 ± 1.20	5.00 ± 0.00 *	0.01	* 0.0078
Laundry (1-3)	<sup>a</sup> 2.00 ± 1.00	2.47 ± 0.83	2.50 ± 0.93	3.00 ± 0.00	0.39	
Transportation (1-5)	2.88 ± 1.55	2.73 ± 1.49	3.50 ± 1.31	4.50 ± 0.58	0.03	
Medication Management (1-3)	1.88 ± 0.83	1.87 ± 0.92	2.38 ± 0.92	3.00 ± 0.00	0.14	
Handling Finances (1-3)	1.50 ± 0.76 *	2.14 ± 0.66	2.25 ± 0.71	3.00 ± 0.00 *	0.03	*0.0097
Bathing (1-3)	1.25 ± 0.71 *	1.53 ± 0.74	1.88 ± 0.83	2.75 ± 0.50 *	0.05	* 0.0164
Dressing (1-3)	1.25 ± 0.71 *	1.53 ± 0.64 †	1.50 ± 0.53	3.00 ± 0.00 * †	0.02	* 0.003 † 0.0197
Toileting (1-2)	1.12 ± 0.35	1.13 ± 0.35	1.25 ± 0.46	1.75 ± 0.50	0.12	
Transferring (1-3)	1.12 ± 0.35	1.20 ± 0.41	1.62 ± 0.52	1.25 ± 0.50	0.12	
Continence (1- 2)	1.62 ± 0.52	1.33 ± 0.49	1.50 ± 0.53	1.75 ± 0.50	0.31	
Feeding (1-2)	1.12 ± 0.35	1.13 ± 0.35	1.12 ± 0.35	1.50 ± 0.58	0.46	

Note. All items in this table are reported by mean ± standard deviation. Possible score ranges for each item are indicated in parentheses beside each ADL title. <sup>a</sup> refers to n = 7. \* represents significant differences between the Little to No Burden group and the Severe Burden group, † represents significant differences between the Mild Burden group and the Severe Burden group.

**Table 9.** Care Partner Burden and Quality of Life Outcomes, Stratified by Zarit Burden Inventory Outcome Groups

PDQ-Carer	Little to No Burden	Mild Burden	Moderate Burden	Severe Burden	<i>p</i> value (Kruskal Wallis)	<i>p</i> value (Dunn's Test)
Personal and Social Activities	21.87 ± 9.77 •*	38.39 ± 14.07 †	68.23 ± 11.51 •	94.79 ± 3.99 * †	0.00	• 0.0006 *0.001 †0.0114
Anxiety and Depression	30.21 ± 15.71 •*	47.62 ± 14.86	68.23 ± 8.89 •	77.08 ± 9.92 *	0.00	• 0.0014 * 0.0022
Self Care	9.38 ± 5.63 •*	31.43 ± 20.52	56.88 ± 13.87 •	76.25 ± 13.77 *	0.00	• 0.0009 * 0.0004
Strain	25.00 ± 11.14 •*	44.34 ± 16.95	64.06 ± 16.95 •	77.09 ± 10.29 *	0.00	• 0.0007 * 0.0006
MBBS	Little to No Burden	Mild Burden	Moderate Burden	Severe Burden	<i>p</i> value (Kruskal Wallis)	<i>p</i> value (Dunn's Test)
Objective	9.38 ± 2.33 •*	14.53 ± 4.03 †	21.00 ± 3.74 •	28.75 ± 0.96 * †	0.00	• 0.0004 * < 0.0001 † 0.0063
Relationship	6.00 ± 6.27 *	7.67 ± 2.97 †	10.75 ± 6.27	17.75 ± 2.87 * †	0.01	* 0.0045 † 0.0116
Stress	8.50 ± 3.07 •*	10.86 ± 2.21 †‡	17.38 ± 2.97 • †	20.00 ± 2.94 * †	0.00	• 0.0004 * 0.0006 † 0.0115 ‡ 0.0122
Global Score	23.88 ± 4.32 •*	32.87 ± 6.74 †	49.12 ± 9.66 •	66.50 ± 5.80 * †	0.00	• 0.0001 * 0.0001 † 0.0078

Note. All items in this table are reported by mean ± standard deviation. MBBS = Montgomery Borgatta Burden Scale; PDQ-Carer = Parkinson's Disease Questionnaire-Carer. \* represents significant differences between the Little to No Burden group and the Severe Burden group, † represents significant differences between the Mild Burden group and the Severe Burden group, • represents significant differences between the Little to No Burden group and Moderate Burden group, ‡ represents significant differences between the Mild Burden group and Moderate Burden group.

Moderate Burden: Care partners in this group (five females, three males) had ZBI scores between 41-60. This group received significantly less formal support than the Severe Burden group ( $p = 0.016$ ) (detailed in Table 6). There were no significant differences between this group and any other groups across any ADL measures (assistance provided or care recipient independence, detailed in Table 7 and Table 8, respectively) in this survey. Scores for all dimensions of PDQ-Carer are significantly higher than that of the Little to No Burden group (Personal and Social Activities,  $p = 0.001$ ; Anxiety and Depression,  $p = 0.0014$ ; Self Care,  $p = 0.0009$ ; Strain,  $p = 0.0007$ ) as well as the MBBS-Objective score ( $p = 0.0004$ ) (detailed in Table 9). The mean Personal and Social Activities ( $68.2 \pm 11.5$ ), Self Care ( $68.2 \pm 8.9$ ) and Strain ( $64.1 \pm 17.0$ ) dimensional scores were also above the threshold indicating seriously compromised quality of life (Jenkinson et al, 2012). MBBS-Relationship was not significantly different from any other group, while MBBS-Stress score was significantly higher than that of both the Little to No Burden group ( $p = 0.0004$ ) and the Mild Burden group ( $p = 0.0122$ ).

Mild Burden: Care partners in this group (12 females, three males) had ZBI scores between 21-40. Across basic ADLs, care partners in this group seldom provided complete assistance, but all care partners in this group provided some assistance in multiple basic ADLs (detailed in Table 7). As compared to the Severe Burden group, care partner assistance provided was significantly lower for bathing ( $p = 0.0098$ ) and toileting ( $p = 0.0218$ ). Across instrumental ADLs, care partners in this group most often provided at least some assistance to their care recipients. However, the only ADL which care recipients were significantly more independent as compared to the Severe Burden group was dressing ( $p = 0.0197$ ) (detailed in Table 8). Across the quality of life outcomes, personal and social activities was the only dimension which care partners were experiencing significantly less difficulty, as compared to the Severe burden group ( $p = 0.0114$ ) (detailed in Table 9). However, when considering the dimensions of burden using MBBS scores, objective ( $p = 0.0063$ ) and relationship ( $p = 0.0116$ ) burden was significantly lower for this group as compared to the Severe burden group. Stress burden was significantly lower than both the Moderate Burden ( $p = 0.0112$ ) and Severe Burden ( $p = 0.0115$ ) groups.

Little to No Burden: Care partners in this group (seven females, one male) had ZBI scores between 0-20. Received weekly formal support was significantly lower ( $p = 0.0079$ ) for this group when compared to the Severe Burden group (detailed in Table 6). These care partners

most often reported providing no assistance across ADLs, especially basic ADLs (detailed in Table 7). Care recipient independence across ADLs followed similar patterns, in that most care recipients were more independent across most basic ADLs, with more dependence observed across instrumental ADLs (detailed in Table 8). However, relative to the higher burden groups, care recipients described by this group were still more independent when compared to the Severe Burden group, as previously discussed. Considering quality of life dimensions, no care partners in this group had any dimensional score above the threshold for seriously compromised quality of life (60.0) (detailed in Table 9). As discussed, all burden outcomes were significantly different from the Severe Burden group and some significant differences emerged with the Moderate Burden group.

In summary, the Severe Burden group provide the highest amount of assistance to their care recipient and report the highest level of care recipient dependence across various ADLs. Significant differences between the Severe Burden group and Little to No Burden groups included assistance with bathing ( $p = 0.0076$ ), dressing ( $p = 0.0099$ ), toileting ( $p = 0.0007$ ), and eating ( $p = 0.0037$ ). However, the amount of time spent as a care partner in weekly hours and in years was similar across all groups. The Severe Burden group had the highest mean access to formal assistance ( $41.8 \pm 33.7$  hours per week), while the Mild Burden group had the highest mean access to informal assistance ( $15.0 \pm 31.9$  hours per week). Across dimensions of quality of life and burden (PDQ-Carer and MBBS scores), the Severe Burden group was most negatively impacted, closely followed by the Moderate Burden group, while the Little to No Burden and Mild Burden groups were much less negatively impacted.

## 5 Discussion

The present study explores the experiences of care partners for PwPD living in Southwestern Ontario, with a specific emphasis on describing burden experienced within this population. This study is the only study, to date, to contribute quantitative data to operationalize the burden experienced by care partners of PwPD in Southwestern Ontario.

Similar to findings in the existing literature on care partners for PwPD (Greenwall et al., 2015; Mosley et al., 2017), most of the care partners in this study were female spouses, which is expected given the proportionally higher incidence of PD in males compared to females (Pringsheim et al., 2014). To the best of our knowledge, this is the only study to date to explore the experiences of non-spousal care partners and male care partners for PwPD living in Southwestern Ontario. In this way, the current study expands and updates the description of care partner experiences for PwPD living in Southwestern Ontario, started by Roland and colleagues (2010).

Consistent with previous studies (Greenwall et al., 2015), there were no significant differences between burden groups on the basis of care partner age or education level. While there were also no significant differences between burden groups on the basis of household annual income in this study, no care partners who completed the outcome measure segments of the survey indicated belonging to the lowest income bracket, below \$25,000 CAD. Additionally, only two participants indicated belonging to the second lowest income bracket, between \$25,000 CAD and \$49,999 CAD; one of these care partners belonged to the Little to No Burden group, and the other belonged to the Severe Burden group. While the results of previous studies have indicated that a very low income may be a predictor of burden (Edwards & Scheetz 2002; Viwattanakulvanid et al., 2014), the present study's participant pool in the lower income brackets is not large enough to support or reject such assertions.

Interestingly, male care partners, on average, experienced more burden than female care partners in this study. Within the context of care partners for PwPD, gender is not universally accepted as a strong mediator of burden (Mosley et al., 2017). Past studies have reported higher burden and depression in female care partners as compared to male care partners (Lyons et al., 2009), which



is consistent with broader literature on care partner experiences, regardless of health condition (Swinkels et al., 2017). One possible explanation for the present finding is a tension for male care partners between traditional male gender roles and the tasks associated with providing care (Xiong et al, 2020), while for female care partners, caring is consistent with socially constructed gender expectations. Using Xiong and colleagues' (2020) explanation, which states that men in care partner roles tend to engage with specific duties less and therefore experience less burden, such a result in the present study may be specifically indicative that the male care partners in this study participate more directly in care duties than is usually described in the broader literature. The mean weekly hours of care provided by the nine male care partners in this study was 82.9, while McLaughlin et al (2011) estimated that care partners, regardless of gender, an average of 50 weekly hours of care. Additionally, in this study, the mean weekly hours of care provided by female care partners was 34.3 (n=21). Further, all eight of the male care partners with completed outcome measures (MBBS, ZBI and PDQ-Carer) were spouses of their care recipients, while female care partners had differing relationships to their care recipients. Since spousal relationships between care partners and PwPD have previously been found to be associated with higher burden compared to other familial and close relationships (Viwattanakulvanid et al., 2014), the nature of the relationship held by the male care partners in the present study may also explain the increased burden observed in this subgroup.

Significant differences were observed across ZBI groups based on weekly hours of formal assistance with care. Specifically, the Severe Burden group accessed formal care assistance significantly more than the Little to No Burden group, and the Moderate Burden group. Considering this study's findings with respect to care recipient independence in ADLs and care partner assistance provided with ADLs, this finding may be another indication that care partners experiencing severe burden are providing care to PwPD with the most functional disability, thus requiring such assistance. Further, care partners experiencing severe burden may deem the formal care accessed essential and may experience stress over financial requirements to access such a necessity. Formal assistance provided to groups with less than severe burden may be appraised as non-essential, but helpful. Alternately, since we do not know the point at which care partners began to access formal care assistance, it is possible that care partners in the Severe Burden group may have reached out for such help later in the course of disease progression, as compared to the other groups. In this way, these care partners may have already started to

experience higher levels of stress and burden within the care role. Accessing formal help may also be associated with feelings of inadequacy within the care role, further contributing to feelings of subjective burden.

ZBI groups were not significantly different from each other with respect to weekly informal care assistance. Mean weekly hours of informal care assistance were  $0.6 \pm 1.8$  for the Little to No Burden group,  $15.0 \pm 31.9$  for the Mild Burden group,  $3.6 \pm 5.3$  for the Moderate Burden group, and  $2.0 \pm 2.45$  for the Severe Burden group. As the standard deviation values would suggest, within each group, zero hours of informal care assistance was a common response in all groups (detailed in Table 6). Since access to informal assistance can be considered an aspect of social support, which is understood to be a protective factor against burden and negative outcomes for care partners (Goldsworthy & Knowles 2008; Edwards & Scheetz 2002), this result is somewhat surprising. However, informal care assistance is only one aspect of a care partner's social support network, and this study did not specifically investigate other aspects of social support. Further, such a finding may support claims about limits to the extent of protection against burden that informal social support can provide to care partners (Goldsworthy & Knowles 2008).

Weekly time commitment to providing care (measured in hours) was also not significant to the level of burden reported by care partners in this study. While some studies have found a link between weekly time commitment to care duties and burden (Zhong et al., 2016; Tew et al., 2013), this is not a consistently reported result with care partners for PwPD (Shin et al., 2012; Martinez-Martin et al., 2008). As such, the present result supports the notion that time, isolated from other markers of care efforts, is insufficient to explain care partner outcomes (Lin et al., 2019). Instead, care partner assistance with basic ADLs (specifically toileting, eating, dressing, and bathing) in this study were significantly different across burden groups. These patterns considered together may suggest that the time devoted to care duties is not as important as the type of care duties taken on. For example, devoting extra time to cook for the PwPD every day may not bare the same emotional significance as assisting the PwPD with dressing themselves, even if, on a weekly basis, more hours are devoted to cooking when compared to dressing.

Disease duration, measured in years, was not found to be significant to when comparing burden groups. This finding may be due to differences in the timing of medical intervention. PwPD with

earlier detection of the disease may have had the diagnosis for longer but may not experience the same severity as other PwPD, diagnosed later in the disease progression. Alternately, this result may indicate different rates of disease progression in PwPD, considering that independence in ADLs and assistance given in ADLs was related to reported levels of burden in care partners. Since care partners may not readily know the clinical PD stage of their care recipient, either measured by the Modified H&Y scale or the MDS-UPDRS, this marker of disease progression was not considered in this study. Importantly, the time commitment for care partners, measured by weekly hours or by years within the care role, has no relationship with burden outcomes, but the type of assistance care partners provide PwPD does impact level of burden in the present study.

### 5.1 Care Partner Assistance with Activities of Daily Living and Burden

Considering care partner assistance with ADLs and care recipient ADL independence together, ZBI groups consistently reported significant differences in experiences surrounding bathing and dressing. As care partners provided more assistance and as care recipients were less independent with these ADLs, the level of burden, as described by ZBI group, increased. This finding suggests that burden may be precipitated by the loss of functional independence in basic ADLs, and in keeping with the broad understanding that disease progression is related to the experience of care partner burden for PwPD (Mosley et al., 2017).

Care partner assistance with toileting was associated with increased burden, while there were no differences across ZBI groups with respect to care recipient continence and care recipient toileting independence. While previous studies specifically focusing on care partners for PwPD have not discussed the impact of toileting on burden, this finding is in keeping with broader literature on care partners experiences with toileting assistance. This finding may suggest that for care partners, directly providing toileting assistance is specifically stressful. One possible explanation for this relationship is the increased time commitment associated with toileting assistance (i.e. multiple instances per day) and potential physical labour related to the specific task. Assisting with toileting also involves a sense of urgency and increased pressure on the care partner. Another possible explanation for this observation is the symbolic representation of toileting assistance for the care recipient. Most frequently, the care partners included in this study

are spouses or adult children to their care recipients. Assistance with toileting may symbolize a shift in the relationship between the care partner and care recipient, which may be a cause of emotional and relational distress. Incontinence or lack of independence with toileting is known to be distressing to individuals with varying health conditions (Mendes et al., 2017; Ostaszewicz et al., 2012) and witnessing such distress could contribute to negative care partner experiences. Moreover, the ability to privately toilet is culturally understood as a more dignified experience for adults. Care partners may feel particularly concerned with maintaining the PwPD's dignity while providing toileting assistance, which could cause internal tension due to such cultural expectations surrounding toileting. While literature specifically related to care partners for PwPD does not highlight dependence in toileting as a specific cause of burden, broader literature describing care partner burden has identified toileting as a problematic symptom of dementia, contributing to burden and to decisions to seek placement in a care facility (Drennan et al., 2012).

Similar to toileting, care partner assistance provided with eating was significantly different across ZBI groups, but care recipient independence in feeding was not significantly different across ZBI groups. This observation may also be explained by the increased daily occurrence of providing such assistance. Mosley and colleagues (2017) suggest that care partner distress related to eating can arise from social aspects of eating. As an activity, eating is often done in public or in the presence of others, and feelings of embarrassment or shame may arise in the PwPD or the care partner when engaging in eating as a social activity, when the activity cannot be done independently. Another possible mechanism for the relationship observed between assistance with eating and burden could be that the social aspect of this activity is reduced. This is to say that the dyad may eat socially less often or not at all, resulting in feelings of increased social isolation. Considering the interpersonal relationship between the PwPD and the care partner, when meals are consumed in private, the assistance required may make eating feel less social; this is to say that the act of eating in company may feel less like it meets a social need for the care partner when there are care duties associated.

## 5.2 Care Partner Outcomes

Expectantly, ZBI groups reporting higher levels of burden also reported a more compromised quality of life, as described by PDQ-Carer scores. Of the dimensions of quality of life, self-care was, on average, the least compromised across burden groups. The Severe Burden group reported the highest average level of compromise in the personal and social activities dimension, when compared to the other PDQ-Carer dimensional scores, while the Mild Burden and Little to No Burden groups reported the highest average level of compromise in the anxiety and depression domain. The Moderate Burden group reported equally high average levels of compromise in the anxiety and depression domain and personal and social activities domain. Importantly, no care partners in the Little to No Burden group reported any score above the severely compromised quality of life threshold of 60, in any dimension. In the Mild Burden group, some care partners reported some dimensional scores above the severely compromised quality of life threshold, but none reported all four dimensional scores above this threshold. In the Moderate Burden group, every care partner reported at least one dimensional score above the severely compromised quality of life threshold, and in the Severe Burden group every care partner reported all dimensional scores above the severely compromised quality of life threshold. These findings were expected based on the linked relationship between quality of life and burden as constructs (Mosley et al., 2017; Hughes et al., 1999). Poor quality of life has been interpreted as a contributing factor to high care partner burden (Leroi et al., 2012), but also as an outcome in its own right that is predicted by the presence of care partner burden (Jenkinson et al., 2012). In either interpretation of this relationship, the present findings support the broad notion that care partner burden and quality of life are related to each other. These findings also may contribute to a more detailed definition of each of the strata of burden set out by the ZBI, but further investigation of this relationship is necessary.

Expectantly, higher global and dimensional burden scores from the MBBS were observed in the ZBI groups reporting moderate and severe burden. In this study, care partner relationship burden, arising from the “demands for care and attention over and above the level that the caregiver perceives as warranted by the care receiver’s condition” (Montgomery et al., 2011, pp.644), was least problematic to overall burden. For every burden group, relationship burden was relatively low, when comparing the group mean in each MBBS dimensional score to the

maximum possible score. This finding may suggest that for care partners who participated in this study, relationship quality may not be a primary driver of the burden they faced. However, specifically focused inquiry of relationship quality and burden would be necessary to confirm.

### 5.3 Limitations

The data presented in this study may not be representative of the target population, since the sample was limited in size. Additionally, self-selection biases based on online volunteer recruitment may have caused exclusion of care partners in Southwestern Ontario; for example, individuals who struggle with reading in English may have been deterred from participation. Since care partner experiences may be described in many ways and are mediated by many factors, as discussed in the literature review, the present study uses a narrow focus on basic demographic characteristics, characteristics of care recipient functional ability and care partner ADL assistance, and burden and quality of life. However, a limitation of this narrow focus is a decreased capacity for an intersectional approach to the exploration of these experiences. Inclusion of further variables, such as race and religious affiliation, would have increased the intersectionality of the present study.

### 5.4 Future Directions

Future studies concerning the care partners for PwPD living in Southwestern Ontario could add to the present work by investigating other known or possible mediators of burden, such as relationship quality, ethnic and racial identity, or religious affiliation, which are each deserving of specific focus. Especially important is an intersectional approach to further study of care partner experiences, as such an approach may elucidate how different identities interact with the care partner identity and influence individual interpretations of the care partner role.

The present study may provide direction for future qualitative inquiry surrounding care partner experiences. Existing literature on care partners for PwPD does not frequently address specific experiences of assisting with basic ADLs, such as toileting or dressing. Since the present results suggest the importance to these activities, future research may investigate the meaning care partners give to these aspects of providing care.

Since this study was conducted, the Covid-19 pandemic has changed many aspects of daily life for all Canadians, and especially for elderly communities (Prime et al., 2020). Investigation of how the pandemic has impacted informal care situations is necessary to reflect the current experiences of care partners in this region. The present study may be used in such context as a reference point to note changes in duties taken on by care partners, the amount of time care partners devote to care, and care partner burden and quality of life outcomes. While care partner outcomes, regardless of diagnosis, for the Southwestern Ontario region or the province of Ontario have yet to be reported, a study from documenting the impact of the Covid-19 pandemic on the care partners living in Alberta (Anderson & Parmar, 2020), including care partners for PwPD, found increase in anxiety and loneliness in care partners, regardless of proximity to their care recipient. Care partners living with their care recipients reported increases in weekly hours spent providing care, while care partners living apart from their care recipients reported increased distress due to physical distancing measures preventing continuation of physical care (Anderson & Parmar, 2020).

To build a more interdisciplinary picture of care partner burden and stress experienced, further research could also include a biological marker for stress. Cortisol is the stress hormone involved in mediating short-term and long-term stress responses (Gaab et al., 2005). Higher circulating cortisol is known to have a suppressive impact on the immune system and decreases bone density. Such an addition would add a biological perspective to the experiences of care partners for PwPD. At present, one study with specific reference to care partners for PwPD includes biological considerations of stress in participants (de Vugt et al., 2005). However, such experiments have been carried out in other care partner populations to biologically operationalize the stress experienced by care partners (Romero-Martinez et al., 2020; Bevans et al., 2016; Davis et al., 2004). Broad findings of these studies report increases in salivary cortisol, circulating cortisol and cortisol in hair in care partners experiencing burden when compared to non-care partner control populations and care partners reporting little burden (Romero-Martinez et al., 2020; Bevans et al., 2016; Davis et al., 2004). Reporting on cortisol levels would provide a stronger link between the subjective experiences of care partners and the biological consequences of such experiences.

## 5.5 Conclusion

The present study provides a quantitative approach to characterizing the burden experience of care partners for PwPD living in Southwestern Ontario. Our findings suggest that the level of disability of the PwPD and care partner involvement in facilitating basic ADLs for the PwPD are associated with the level of burden experienced by the care partners in this study. Facilitating PwPD toileting and eating were associated with burden in care partners in this study, regardless of PwPD level of independence in these activities. Male care partners reported higher average levels of burden, compared to female care partners, but also reported above average involvement in time commitment within care duties. Importantly, the number of years spent in the care role, number of years since diagnosis, and weekly hours spent providing care were not significantly different across burden outcome groups in this sample. Further study is necessary to elucidate how other identities care partners possess may influence experiences within the care partner role. Future research may also refer to the present study as a representation of care partner experiences in the year before the onset of the COVID-19 pandemic.



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