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A cross-cultural examination of the relations among Parkinson's disease impairments, caregiver burden and mental health, and family dynamics in Mexico and the United States

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A CROSS-CULTURAL EXAMINATION OF THE RELATIONS AMONG PARKINSON'S DISEASE IMPAIRMENTS, CAREGIVER BURDEN AND MENTAL HEALTH, AND FAMILY DYNAMICS IN MEXICO AND THE UNITED STATES

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Abstract

Parkinson's Disease (PD) is a common progressive neurodegenerative disorder that leads to both physical and cognitive impairment over time. Eventually, these impairments may include the loss of autonomy, and the individual may require the assistance of an informal caregiver. Informal caregivers are critical in the care of individuals with PD and spend substantial time providing care, which may be associated with negative caregiver outcomes such as burden, mental health issues, as well as poor family dynamics. Although research in the United States and Europe has generally supported these relations, there is very limited research on PD caregiving in Latin America. Given the rapidly aging population of Latin America, research suggests that the prevalence of PD is likely to increase substantially. Although cultural values such as familism may encourage informal caregiving in Latin America, very little is known about either PD patient or caregiver experiences in the region and how they may differ from those in the United States and Europe.

As such, the current study built upon Pearlin's caregiving stress process model to examine how PD-related impairments, caregiver burden and mental health, and family dynamics may differ between the United States and Mexico and to examine connections among the following variables in a sample of PD caregivers from the United States and Mexico: (a) PD-related impairments (motor and non-motor symptoms) and caregiver burden, (b) caregiver burden and caregiver mental health, (c) PD-related impairments and mental health through caregiver burden, and (d) family dynamics which may moderate these relations.

The current study consisted of caregivers of individuals with PD (total $N = 253$) from the United States ($N = 105$) and Mexico ($N = 148$). A series of t-tests and mediational models were

conducted to determine the connections among PD-related impairments, caregiver burden and mental health, and family dynamics. Results suggested that caregivers from the United States site experienced higher levels of caregiver burden, although there were no significant differences in caregiver mental health. Further, caregiver burden fully mediated the relation between PD-related impairments and caregiver mental health at both study sites, although family dynamics did not moderate these mediational models as hypothesized. Despite the importance of cultural values such as familism in Latin America, family dynamics explained more variance in the model at the United States site than at the Mexico site. Exploratory analyses found that caregivers from the Mexico site more frequently reported suicidal and self-injurious thoughts but did not find a significant disparity in self-reported gender of the caregiver.

Overall, the current study identified significant relations among PD-related impairments, caregiver burden and mental health, and family dynamics among caregivers of individuals with PD from the United States and Mexico. Findings from the current study highlight a number of important interventions for caregivers and families, including caregiver burden and mental health, as well as family dynamics.

Overview

The literature review will begin by first providing an overview of the epidemiology, pathophysiology, clinical course, symptoms, and treatment of Parkinson's disease (PD). The review will then outline the responsibilities of informal PD caregivers and describe the concepts of caregiver burden and caregiver strain. Then, it will describe the research on the following topics: (a) PD-related impairments (both motor and non-motor symptoms) and caregiver burden, (b) caregiver burden and caregiver mental health, and (c) PD-related impairments and caregiver mental health. Following this, the role of the family in informal caregiving and family dynamics will be described with a focus on neurological conditions and a summary of this literature in PD. Then, a review of cultural values in Latin America, such as familismo, marianismo and machismo, and religiosity, that may encourage the practice of informal caregiving in Latin America, will be discussed as well as a review of the PD literature in Latin America, with a focus on Mexico where the majority of this research has been conducted. The objectives of the current study will be outlined followed by the study methods and data analysis plan and study results. Finally, the discussion will discuss the results of the current study in light of prior literature, outline important clinical implications, and discuss limitations of the current study and future directions for research.

Chapter 1: Literature Review

Parkinson's disease (PD) is a progressive neurodegenerative disease that leads to physical disability (Shulman et al., 2016) and cognitive impairment (Petrou et al., 2015) over time, both of which may limit an individual's independent functioning. PD is the second most common progressive neurodegenerative disease in the United States (de Lau & Breteler, 2006), affecting 1-2 individuals per 1,000 of the population (Tysnes & Storstein, 2017) and approximately 1% of individuals over the age of 60 (Nussbaum & Ellis, 2003). Recent estimates suggest that by 2030, there will be approximately 1.2 million individuals in the United States living with PD (Marras et al., 2018).

Given the progressive nature of the disease, impairment increases over time, leading most individuals living with PD to require the assistance of a caregiver. This care is often provided by an informal caregiver, an individual who does not receive financial compensation for caregiving and is often a family member (Buchanan, Radin, Chakravorty, & Tyry, 2010; Zucchella, Bartolo, Pasotti, Chiapella, & Sinforiani, 2012). Informal caregivers support the individual living with PD by performing a number of physical, social, and emotional tasks, which may include assisting with personal care and activities of daily living (e.g., bathing, feeding, administering medications), transportation and mobility assistance (e.g., getting in and out of bed), providing social and emotional support, as well as financially supporting the individual living with PD (Bhimani, 2014; McLaughlin et al., 2011; National Alliance for Caregiving, 2015).

Due to its rapidly aging population (Wong & Palloni, 2009), rates of PD are likely to rapidly increase in Latin America, with estimates suggesting the prevalence of PD will double in Mexico within 20 years (Cantu-Martinez et al., 2014) as rates of PD increase with age (Hindle, 2010). In Latin America, family members are more likely to serve as informal caregivers due to

sociocultural values of the region, such as familism, marianismo, and religiosity. Research on the economic impact of PD in Mexico suggests that PD costs over $9,000 United States dollars (USD) per patient annually between fixed (e.g., treatment) and variable costs (e.g., support devices, diagnostic imaging) which is more than the average monthly salary (Cantu-Martinez et al., 2014).

However, despite the high prevalence and increasing rates of PD in Latin America (GBD 2016 Parkinson's Disease Collaborators, 2018), very little is known about either PD patient or caregiver experiences in the region. There are an estimated 129,124 individuals living with PD in Central Latin America, 30,717 in Andean Latin America, and 131,748 in Tropical Latin America (GBD 2016 Parkinson's Disease Collaborators, 2018). As noted by Carod-Artal, Mesquita, Ziomkowski, and Martinez-Martin (2013), inclusion of individuals living with PD from different cultural contexts may lead to early identification and appropriate interventions to address caregiver burden. Further, a more in-depth understanding of their lived experiences may serve to better support individuals living with PD as well as their families through evidence-based interventions and ancillary supports. Although examining caregiving for individuals with neurological conditions in this region is critical, only a small number of studies have been conducted in Latin America, with only a few studies focusing on PD specifically (e.g., Rodríguez-Violante, Camacho-Ordoñez, Cervantes-Arriaga, González-Latapí, & Velázquez-Osuna, 2015).

The Introduction will provide an overview of the epidemiology, pathophysiology, clinical course, symptoms, and treatment of PD. Second, an overview of the interrelations between PD-related impairments, caregiver burden, family dynamics, and mental health will be presented. Finally, a review of familism, marianismo and machismo, and religiosity, sociocultural values

that may influence caregiving in Latin America will be discussed as well as a review of the PD literature in Latin America, with a focus on Mexico where the majority of this research has been conducted.

Epidemiology

Research suggests that PD is an age-related disease, as its onset is rare before age 50 and its prevalence increases with age (Benito-León et al., 2003; Clavería et al., 2002; de Rijk et al., 1995; de Rijk et al., 2000; Errea, Ara, Aibar, & de Pedro-Cuesta, 1999; Morens, White, & Davis, 1996; Schoenberg et al., 1988; Tison et al., 1994). Prior research has found that PD affects approximately 1% of the population over age 60 in industrialized countries (Nussbaum & Ellis, 2003) and approximately 2.6% of individuals over age 85 (Pringsheim, Jette, Frolkis, & Steeves, 2014).

Whether or not PD prevalence varies across race or ethnicity has been contested (Kurtzke & Goldberg, 1988; Lilienfeld et al., 1990; Marttila & Rinne, 1981; Mayeux et al., 1995; Richards & Chaudhuri, 1996), largely due to both a lack of research literature in this area as well as poor measures of race and ethnicity, only including White/European-American or Black/African-American participants, or including small sample sizes of individuals of other races and ethnicities (e.g., Latinx, Asian, and Native American individuals; Dahodwala et al., 2009; Hemming et al., 2011; McInerney-Leo, Gwinn-Hardy, & Nussbaum, 2004; Yacoubian, Howard, KIssela, Sands, & Standaert, 2009). However, at least one study has suggested that rates of PD may be higher in individuals who self-identify as Hispanic or Latino compared to individuals who self-identify as non-Hispanic White, Asian, or Black (Van Den Eeden et al., 2003).

To date, very little research has examined the epidemiology of PD in regions outside of the US and Canada. The majority of this epidemiological research has focused on data derived

from medical records or drug consumption data (Pringsheim et al., 2014). This is problematic for developing countries, as these estimates inherently exclude individuals who are unable to obtain medical care or prescription drugs to treat PD (de Rijk et al., 1997). Further, these studies have also not considered the unique culturally determined treatment practices and varying access to care for PD throughout the world (Chiò, Magnani, & Schiffer, 1998).

A recent international meta-analysis on the prevalence of PD conducted by Pringsheim et al. (2014) was only able to identify four studies in South America that used rigorous methodology for estimating the prevalence of PD (i.e., first assessing symptomatology through self-report measures followed by a formal diagnosis by a physician). Although PD prevalence is similar across North America, Europe, and Australia, the sample sizes from studies conducted in South America were too small to make meaningful comparisons between regions.

Similarly, there is very little research that has made any comparisons between individuals living with PD in any part of Latin America and the rest of the world. A review of the literature yielded one study that examined a registry of individuals living with PD in Mexico. Analyses of this registry found that participants were of similar age to individuals in registries from other countries (Cervantes-Arriaga et al., 2013). However, individuals in the registry were less educated, had a longer period from the onset of PD symptoms to diagnosis, and did not use dopamine agonists as frequently to address PD symptoms (Cervantes-Arriaga et al., 2013).

Pathophysiology

Although research continues to examine the underlying causes of PD, its etiology is still not fully understood. According to Caviness (2014), PD represents a cascade of dysfunction at multiple levels. First, genetic influences may lead to cellular and tissue abnormalities. These abnormalities may alter, damage, or kill dopamine neurons in the substantia nigra region of the

brain, a critical feature of the disease. The lack of dopamine in the brain ultimately influences an individual's behavior and plays a critical role in the development of motor symptoms of the disease (Caviness, 2014).

Despite the number of causative genetic mutations that have been identified in recent years, these mutations are not able to explain the majority of PD cases (Cainess, 2014; de Lau & Breteler, 2006). Indeed, research demonstrates that approximately 90% of cases are instead sporadic (de Lau & Breteler, 2006), suggesting that there are other important factors that may contribute to the development of PD.

Diagnosis and Disease Course

Due to the lack of a definitive test to diagnose PD and the similarities between PD and other neurological conditions, PD may be difficult to diagnose. Prior research has found that between 75% to 95% of individuals diagnosed with PD during their lives have a confirmed diagnosis post mortem (Hughes, Daniel, Kilford, & Lees, 1992; Hughes, Daniel, & Lees, 2001; Litvan et al., 1998; Rajput, Rozdilsky, & Rajput, 1991; Tolosa, Wenning, & Poewe, 2006), suggesting that at least some cases are misdiagnosed. It is currently not possible to achieve full diagnostic certainty during life (Postuma et al., 2015), as pathological confirmation of Lewy bodies during autopsy is required (Gibb & Lees, 1988). Therefore, in clinical practice, a diagnosis is based on the presence of cardinal motor features, additional associated and exclusionary symptoms, as well as an individual's response to L-Dopa (Rao et al., 2003).

Early work by Hoehn and Yahr (1967) outlined the stages of progression of PD, which are referred to as the Hoehn and Yahr stages. In stage I, there is typically minimal to no functional impairment, and involvement is generally unilateral. Stage II is characterized by bilateral involvement, but balance is yet to be impaired. Unsteadiness first appears in stage III,

where individuals may not be able to right themselves if pushed while standing. In this stage, individuals may still be capable of taking care of themselves. By stage IV, PD is considered fully developed and severely disabling. At this point in the disease trajectory, the individual living with PD may still walk or stand without assistance. By stage V, the individual generally uses a wheelchair or is unable to leave their bed. As noted by Poewe (2006), PD progression throughout these stages may not always be linear. For example, there are typically more severe declines in motor functioning earlier in the disease versus later in the disease (Poewe, 2006).

Epidemiological studies suggest that PD is associated with reduced life expectancy (Elbaz et al., 2003; Morens et al., 1996). On average, individuals with PD live 15 years post-diagnosis (Lees, Hardy, & Revesz, 2009), although many individuals with PD are living even longer due to treatment advances (Lee & Gilbert, 2016). However, progression of the disease may vary greatly from one individual to another. For example, age of diagnosis may be important in the disease course of PD. Individuals who are diagnosed with PD at younger ages tend to live longer than individuals who are diagnosed later (Ishihara, Cheesbrough, Brayne, & Schrag, 2007).

Symptoms

PD is characterized by its classic motor symptoms, including akinesia (loss or impaired voluntary movement), bradykinesia (slowness of movement), resting tremor (shaking while in a relaxed state), and postural instability (Mandir & Vaughan, 2000). Individuals may present with additional motor symptoms, including gait problems (Forsaa, Larsen, Wentzel-Larsen, & Alves, 2015) as well as reduced facial expression (Ricciardi et al., 2015). Although motor parkinsonism remains a critical feature of the disease, increasing attention has been given to the non-motor manifestations of PD. Typically, by the time an individual is 10 years post-diagnosis, the

individual will present a number of non-motor symptoms (Poewe, 2006). Non-motor symptoms of PD may include depression, cognitive impairment, apathy, anxiety, sleep disruption, dementia, and psychosis (Mosley, Moodie, & Dissanayaka, 2017).

Treatment

Unfortunately, there is no cure (Connolly & Lang, 2014) or neuroprotective therapy for PD (AlDakheel, Kalia, & Lang, 2014). As such, pharmacological therapies aim to improve quality of life through symptom reduction. Pharmacological treatments are typically initiated when individuals living with PD experience impairment or embarrassment due to their symptoms (Connolly & Lang, 2014). In the beginning stages of the disease when symptoms are mild, monoamine oxidase type B inhibitors (MAOBIs) such as selegiline or rasagiline may be prescribed, which have been shown to reduce symptomatology (Ives et al., 2004). Dopamine agonists may also be effective in the early stages of PD (Fox et al., 2011). When activities of daily living become impaired, dopamine agonists, or levodopa (L-dopa), are commonly used (Connolly & Lang, 2014), with L-dopa being the most popular pharmacological treatment (Mandir & Vaughan, 2000).

L-dopa functions by increasing levels of dopamine in the brain, which are depleted in individuals with PD (Connolly & Lang, 2014). L-dopa is often administered in tandem with carbidopa, a decarboxylase inhibitor in order to avoid the peripheral conversion of L-dopa to dopamine, which maximizes its delivery within the brain (Mandir & Vaughan, 2000). To date, L-dopa is the most effective pharmacological treatment for PD (Mandir & Vaughan, 2000) and has been associated with a reduction in freezing, edema, somnolence, risk of impulse control disorders, and hallucinations compared to dopamine agonists (Ferreira et al., 2013).

Although initial treatment with L-dopa is effective, PD becomes more resistant to treatment as non-dopaminergic brain regions become involved with progression of the disease (Connolly & Lang, 2014). Dopamine-mediated treatments also do not directly influence the degenerative processes that cause PD (Korczyn & Hassin-Baer, 2015). Therefore, despite the significant advances in understanding the pathology of PD, molecular mechanisms involved, and genetic contributions to its development, these advances have yet to impact pharmacologic interventions for patients (Suchowersky et al., 2006). Although dopamine agonists and L-dopa may help address PD symptomatology, these medications may have a number of adverse side effects. These adverse effects may include nausea, impulsive behaviors (including impulse control disorders), dopamine dysregulation syndrome, and psychosis (Connolly & Lang, 2014).

PD Caregiver Responsibilities and Burden

Individuals living with PD often require others to provide care for them in multiple settings and domains of life. In addition to outpatient health care services from health care professionals such as occupational, speech, physical, and recreation therapies, informal caregivers such as family or friends provide care for individuals living with PD (Bhimani, 2014). Despite the number of studies examining PD caregivers, there is scant literature on how they actually provide care and rehabilitation for individuals living with PD (Bhimani, 2014). However, research suggests that informal caregivers may be responsible for administering medications, coordinating care, communicating and advocating on behalf of the individual living with PD, and providing financial and emotional support, while also directly assisting the individual with PD in activities of daily living (e.g., bathing, feeding; Mosley, Moodie, & Dissanayaka, 2017).

Providing care may come at a significant cost to the caregiver, such as giving up a career, leisure activities, or social activities to take care of the individual living with PD (Bhimani, 2014). These factors contribute to the caregiver being what has been described as the "invisible patient," and the toll on a caregiver's life may diminish the overall effectiveness of the informal caregiver (Mosley et al., 2017). Research suggests that providing care for an individual with PD may have negative consequences for the caregiver, such as having a lower quality of life than the general population (Martínez-Martín et al., 2007; Martinez-Martin Pablo et al., 2008).

Caregivers have a number of tasks that they must complete to support the individual (e.g., activities of daily living), which they may not have performed prior to the individual developing PD. These substantial life changes may result in caregiver burden, a multidimensional construct that has been operationalized in a number of ways. For example, Zarit, Todd, and Zarit (1987) described caregiver burden as encompassing the adverse effects caregiving may have on an individual's emotional, financial, social, physical, and spiritual function, which may engender feelings of discomfort due to the demands, time constraints, duties, and difficulties with providing care for an individual. Later researchers built upon this definition by adding the internal conflict that caregivers may experience when they are unable to fulfill their personal needs due to caregiving (Braithwaite, 1996), as well as including the reactions informal caregivers may have to the emotional, social, physical, and financial difficulties that result from providing care (Kasuya, Polgar-Bailey, & Takeuchi, 2000). Caregiver burden is critical to examine, as a continued sense of burden may lead to a reduced sense of well-being and burnout (Thornton & Travis, 2003), which can reduce the effectiveness of the caregiver in providing informal care (Mosley et al., 2017).

Caregiver strain is another term that may describe negative feelings associated with caregiving. In general, the terms *caregiver strain* and *caregiver burden* are used interchangeably throughout the literature. Caregiver strain consists of the emotional and physical stress that a caregiver experiences as a result of providing care (Hunt, 2003) and is often conceptualized as the "felt difficulty in performing the caregiver role" (Archbold, Stewart, Greenlick, & Harvath, 1990, p. 376). Caregiver strain specifically consists of goal discrepancy distress, emotional arousal, and exhaustion from providing care to another individual (England & Roberts, 1996), whereas caregiver burden is a broader term that may encompass an individual's emotional, financial, social, physical, and spiritual function (Zarit et al., 1987).

PD-Related Impairments and Caregiver Burden

PD is characterized by its motor symptoms (Mandir & Vaughan, 2000), and over time, individuals may lose autonomy due to these symptoms (Shulman et al., 2008); therefore, a core function of caregivers is to assist the individual as they experience these symptoms. For example, caregivers may administer medication (Mosley et al., 2017) when the presence of symptoms prevents the individual from doing so on their own. A number of studies have examined how motor and non-motor impairments may affect caregiver outcomes, such as caregiver burden, which will be briefly summarized.

Motor Impairments and Caregiver Burden/Strain. One of the first studies to examine motor symptoms and caregiver burden was by Carter et al. (1998), who examined PD spousal caregivers and found that individuals who were rated by clinicians to be in the later Hoehn and Yahr stages of PD had higher caregiver strain scores than those in early stages. Other studies generally support the relationship between motor impairments and burden. For example, Martínez-Martín et al. (2007) examined Hoehn and Yahr staging and caregiver burden in a

sample of Spanish caregivers and found that PD severity was a primary predictor of caregiver burden, suggesting that PD-related impairments are associated with caregiver burden.

Non-Motor Impairments and Burden and Strain. In recent years, increasing attention has been giving to the non-motor symptoms of PD, which may include symptoms such as depression, cognitive impairment (e.g., dementia, executive functioning), apathy, sleep, and anxiety (Mosley et al., 2017), which may be difficult for caregivers to address. Cognitive impairment is prevalent in PD and represents a challenge for informal caregivers, as it limits independent functioning of the individual living with PD. Specifically, research on cognitive impairment and caregiver burden has focused on dementia and executive functioning. Anywhere from 25-40% of individuals living with PD eventually develop dementia (Elbaz et al., 2003). Dementia is a challenge for informal caregivers, as individuals with dementia suffer from functional impairment and often have deficits in memory, executive functioning, and attention from the caregiver (Mosley et al., 2017). Leroi, McDonald, Pantula, and Harbishettar (2012) examined 127 individuals with PD and mild cognitive impairment, with dementia, and those without cognitive impairment as well as 102 caregivers. The study found that caregiver burden was significantly higher in caregivers who cared for an individual living with PD and dementia than those without cognitive impairment or with mild cognitive impairment, suggesting that dementia is independently associated with increased caregiver burden.

Executive functioning represents another aspect of cognitive impairment in PD that may engender caregiver burden, as deficits in executive functioning are associated with a reduced ability to plan for the future or engage in goal-directed behavior (Mosley et al., 2017). Given that tasks important to PD care include goal-oriented behavior (e.g., medication adherence), these deficits may influence outcomes in the patient or otherwise require greater attention from the

caregiver. Kudlicka, Clare, and Hindle (2014) sought to determine how deficits in executive functioning are associated with caregiver burden. In this study, caregivers and individuals living with PD completed the Behaviour Rating Inventory of Executive Function (BRIEF-A, adult version; Roth, Isquith, & Gioia, 2005), which assesses an individual's ability to regular their behavior and emotional responses. Interestingly, only caregiver-reported scores on the BRIEF-A were associated with caregiver burden. Further, multiple regressions including depression and general cognition in the individual living with PD, BRIEF-A scores, and Hoehn and Yahr staging as predictors found that only caregiver-reported BRIEF-A scores and Hoehn and Yahr stage scores predicted caregiver burden, suggesting that caregiver-perceived difficulties with executive function as well as PD stage are independent predictors of caregiver burden.

A wide body of research has also begun to examine mental health deficits (i.e., depression and anxiety) in individuals living with PD and their relation to caregiver burden. Depression is a critical non-motor symptom to study, as it may manifest in lack of enjoyment, guilt, sadness, and even suicidality, which may lead to a reduction of warmth in the relationship between the individual and the caregiver (Mosley et al., 2017). As depression may lead to a reduction in motivation, the caregiver may have greater demands placed on them (Mosley et al., 2017). Anxiety is another common non-motor symptom of PD. In PD, some individuals may have generalized anxiety, panic disorder, social phobia, tension, stress, and irritability (Dissanayaka et al., 2014). Anxiety may be taxing for the caregiver of the individual living with PD for a number of reasons, as anxiety may lead the individual to avoid situations, which may present as agoraphobia (Mosley et al., 2017). This may limit how often the caregiver is able to leave the home. Mosley et al. (2017) also notes that anxiety may lead the individual to excessively rely on the caregiver.

Research suggests that depression and anxiety in individuals living with PD is associated with caregiver burden. For example, in a Brazilian sample of caregiver-patient dyads, Carod-Artal, Mesquita, Ziomkowski and Martinez-Martin (2013) found that patient-reported depression and anxiety symptoms were significantly correlated with caregiver burden. Another study by Ozdilek and Gunal (2012) of caregiver-patient dyads also noted that self-reported depression and anxiety in the individual living with PD are independent predictors of caregiver burden, particularly in later stages of the disease, further supporting that depression and anxiety in individuals living with PD are associated with caregiver burden.

Apathy is another index of mental health that individuals living with PD may experience, which may include reduced emotion, interest, and motivation (Robert et al., 2002). Given that individuals with symptoms of apathy may be less able to express warmth, their caregiver may struggle with reduced positive feedback (Mosley et al., 2017). To date, there is evidence that apathy is associated with caregiver burden. For example, Leroi et al. (2011) examined dyads of individuals living with PD and their caregivers and found that apathy reported by the individual living with PD was associated with increased caregiver burden, while individuals living with PD without behavioral disturbances had caregivers who reported little to no caregiver burden.

Impulse control disorders (ICDs) may also manifest in individuals living with PD as a result of pharmacological treatments that aim to increase levels of dopamine in the brain (Weintraub et al., 2010). These disorders encompass behaviors such as compulsive shopping, gambling, and hypersexuality (Weintraub et al., 2010). Although there is a wide body of literature that examines ICDs in PD broadly, few studies have extended this literature to encompass caregiver experiences. The previously mentioned study by Leroi et al. (2011) also assessed impulsivity and caregiver burden and found that caregivers of individuals with PD and

high levels of impulsivity had significantly higher levels of caregiver burden compared to those with only PD, suggesting that impulsivity is a unique contributor to caregiver burden.

Another study by Okai et al. (2013) conducted examined whether 12 sessions of a cognitive behavioral therapy (CBT) based intervention delivered to individuals living with PD over the span of six months were effective in reducing caregiver burden in caregivers of individuals living with PD with ICDs compared to those solely with PD. Although the frequency and impact of impulse control behaviors were reduced in the treatment group, caregiver burden did not significantly decrease. As noted by Mosley et al. (2017), there may be long-lasting consequences to behaviors associated with ICDs (e.g., debt due to pathological gambling), which may lead to negative feelings in the caregiver that may not resolve in a short time span, such as the six-month time period in the Okai et al. (2013) study.

Sleep is another non-motor symptom of PD that impacts individuals living with PD and caregivers alike. Sleep disturbances are often associated with other symptoms of PD, including depression, hallucinations, or pain (Mosley et al., 2017). Given that spouses are often caregivers, they may share the same bed as the individual with PD and therefore their sleep may also be affected. Even if the caregiver does not sleep in the same bed, the individual with PD may require assistance throughout the night (e.g., turning over in bed, getting out of bed), which may also disturb the sleep of the caregiver (Mercer, 2015). Sleep disturbance is common in caregivers of individuals with PD, with 55% reporting poor sleep quality (Cupidi et al., 2012). This is critical, as sleep disturbance is a risk factor for depressive symptoms in the caregiver (Cupidi et al., 2012; Pal et al., 2004; Smith, Ellgring, & Oertel, 2015) and has also been associated with caregiver burden (Happe & Berger, 2002).

Research on PD impairment and caregiver burden generally examines the motor and non-motor symptoms of PD separately. Of studies that have examined both motor and non-motor symptoms in tandem, very few have included a measure of caregiver burden. For example, Carter, Stewart, Lyons, and Archbold (2008), examined caregiver strain in spousal caregivers of individuals in the early or middle stage of PD and analyzed data taken from a larger clinical trial that included indices of motor symptoms. The non-motor symptoms examined included cognitive function and depression. Hierarchical regression analyses demonstrated that motor symptoms explained from 0-6% of caregiver strain while non-motor symptoms explained 7-13%, suggesting that non-motor symptoms contribute more to caregiver strain than motor symptoms. This may be in part due to the dominant focus on the treatment of motor symptoms in PD management while non-motor symptoms are missed or not discussed during routine consultations with health care providers (Chaudhuri et al., 2010). There is still a reluctance to treat non-motor symptoms (Pfeiffer, 2016) and limited treatment options (Seppi et al., 2019). As such, this may be a potential explanation for the importance of non-motor symptoms and their contribution to caregiver strain in prior research.

Caregiver Burden and Mental Health

The mental health of caregivers of individuals living with PD has been found to be lower than that of the general population (Peters, Fitzpatrick, Doll, Playford, & Jenkinson, 2011), suggesting that caregiving may take a toll on an individual's mental health. Depression and anxiety specifically may be critical to examine as they may elicit cognitive biases that engender greater feelings of caregiver burden (Mosley et al., 2017), and research has demonstrated that depression and anxiety are linked to caregiver burden. For example, Grün et al. (2016) found that caregivers experiencing symptoms of depression and anxiety had higher levels of caregiver

burden than caregivers without depression and anxiety. Similarly, (Caap-Ahlgren & Dehlin, 2002) found that depressive symptoms were associated with caregiver burden in a Swedish sample of PD caregivers.

At least one study has suggested that the link between depression and caregiver burden may be particularly critical in PD compared to other neurological diseases (e.g., Alzheimer's disease). For example, Shin, Youn, Kim, Lee, and Cho (2012) found that caregiver depression and motor activities of daily living in patients predicted caregiver burden in PD, while quality of life, depressive symptoms in the individual living with Alzheimer's disease, cognitive function, and activities of daily living status were predictive of burden among caregivers of individuals with Alzheimer's disease.

PD-Related Impairments and Mental Health

Prior research has linked both motor and non-motor PD-related impairments with caregiver depression. For example, Fernandez, Tabamo, Raymund, & Friedman (2001) found that PD severity, depression in the individual living with PD, and length of disease duration were associated with depressive symptoms in spousal caregivers. In a stepwise regression analysis, only PD duration was a significant predictor of caregiver depression; however, this may be in part due to the strong associations between symptom progression, severity, and disease progression. Later research by Martinez-Martin et al. (2008) also found an association between caregiver depression and depression in the individual living with PD, symptom severity, and disease duration in a sample of Spanish caregivers.

Similarly, caregiver anxiety has also been associated with PD-related impairments. For example, Martinez-Martin et al. (2008) found that 21.7% of PD caregivers experienced anxiety while 9.1% experienced depression, suggesting that anxiety may be more prevalent than

depression among PD caregivers. In the sample, 12.2% of caregivers were being treated for anxiety and 8.8% were using antidepressants. Findings also indicated that caregiver anxiety was associated with PD disease severity, duration of care, as well as female sex.

The Role of Family in PD Caregiving

In general, caregivers of individuals with PD tend to be family members, particularly spouses (Leiknes, Lien, & Severinsson, 2015). PD does not solely affect the individual diagnosed with the disease, as those around the individual must also alter their daily lives in order to provide care (Carter et al., 2008). Further, after diagnosis and throughout the disease trajectory, families may be adjusting to losing financial resources and leisure time (Mosley et al., 2017) as well as adjusting to new roles as a caregiver (Dickson, O'Brien, Ward, Allan, & O'Carroll, 2010). Therefore, the family system warrants attention in the literature and is supported by research in other neurological conditions.

For example, poor family functioning has previously been shown to negatively affect both patients and their caregivers in other neurological condition populations (e.g., dementia, multiple sclerosis). One study found that poor family functioning was associated with depression and anxiety in caregivers of individuals with mild to moderate dementia (Tremont, Davis, & Bishop, 2006). Poor family functioning has also been associated with reduced time spent on caring for patients with Alzheimer's disease (Lieberman & Fisher, 1999), which may influence the quality of care provided by the informal caregiver. Unmet family needs have also been associated with caregiver burden and mental health deficits in caregivers of individuals with spinal cord injury (Arango-Lasprilla et al., 2010).

However, there are relatively few studies that examine the effects of PD on the family system. One such study by Goldsworthy and Knowles (2008) sought to examine whether the

relationship between the caregiver and the individual living with PD may buffer the effects of caring on caregiver burden and quality of life. Findings indicated that relationship quality mediated the association between the effects of caring and caregiver burden as well as quality of life, such that caregivers with higher quality relationships with the individual they cared for experienced less burden and greater quality of life. This research suggests that relationship quality may ameliorate the negative effects of caregiving (e.g., burden).

Research on family functioning and caregiver burden has also been extended to include adolescent and adult children. For example, Schrag, Hovris, Morley, Quinn, and Jahanshahi (2006) examined a sample of 89 children of individuals living with PD. Schrag et al. (2006) found that family functioning and burden of daily help impacted participants the most. Further, the study found higher burden of daily help in children younger than 25 years of age than children older than 25 years of age. However, children older than 25 reported greater impairments in family functioning than children younger than 25 years old. This study may suggest that younger children caregivers feel more burden, while older children caregivers feel PD has had more of an impact on overall family functioning.

Cultural Influences on Caregiving

To date, very little research has examined PD in regions outside of North America and Europe. The majority of research conducted outside of these regions has focused on data derived from medical records or drug consumption data (Pringsheim et al., 2014). This is problematic for developing countries, as these estimates inherently exclude individuals who are unable to obtain medical care or prescription drugs to treat PD (de Rijk et al., 1997). Further, these studies have also not considered the unique culturally determined treatment practices and varying access to

care for PD throughout the world (Chiò et al., 1998). As such, there is a critical need to examine PD caregiving in diverse regions of the world, such as Latin America.

Caregiving in Latin America

In Latin America, an individual is most likely to have a family member serve as an informal caregiver due to allocentric and collectivistic values and norms that emphasize placing the well-being of the family over the self and the use of families to provide informal care of older individuals (Hinojosa, Zsembik, & Rittman, 2009; Oyserman, Coon, & Kemmelmeier, 2002). This is critical, as Latin American countries are projected to experience substantial increases in the number of individuals over 60 years of age over the next four decades (Saab, 2011), with research estimating that older individuals will outnumber younger individuals by roughly 30% (Economic Comission for Latin America and the Caribbean, n.d.). This suggests that there is likely to be an increase in older individuals who will require continuing care. Further, given cultural values of the region, this may lead to an increase in informal caregiving. Therefore, a critical examination of caregiving in Latin America is needed.

Although there is an emerging body of caregiving studies on individuals with neurological diseases in Latin America, thus far it has primarily focused on caregivers of individuals with dementia, multiple sclerosis, traumatic brain injury, and spinal cord injury (Coleman et al., 2013; Elnasseh et al., 2016; Mickens et al., 2018; Moreno et al., 2015; Perrin et al., 2013). Research on other neurological conditions such as PD and their caregivers remains relatively unexplored.

Familismo

Similar to other collectivistic cultures, the concept of *familismo* (familism) may influence roles, obligations, and expectations within families in Latin America (Zea, Quezada, & Belgrave,

1994). *Familismo* is a cultural value that has been described as consisting of three elements: relying on members of the family for assistance, perceiving family members as behavioral referents, and perceiving the obligation to care for family members through material and/or emotional support (Marin & Marin, 1991). The concept of *familismo* also emphasizes the importance of caring for one's family and their needs over one's own needs, as well as a respect for elder individuals in the family (Ruiz & Ransford, 2012). Taken together, the components of *familismo* may contribute to an individual providing informal care for a family member, suggesting it is an important cultural value to consider within the caregiving literature.

Given the cultural importance of *familismo*, families who are unable to meet the needs of the individual requiring care may engender feelings of stress and guilt (Crist, 2002). Indeed, Latino informal caregivers are less likely to institutionalize the individual they provide care for (Dilworth-Anderson, Williams, & Gibson, 2002) and are less likely to use formal support services (Dilworth-Anderson et al., 2002; Pinquart & Sörensen, 2005), which may be in part due to stress and guilt. *Familismo* may also be associated with positive outcomes in the caregiving context. For example, higher levels of *familismo* were associated with lower burden among one sample of Latino caregivers (Coon et al., 2004). When compared to individuals of other racial or ethnic groups, Latino informal caregivers have less desire to stop providing care and are more satisfied in their role as a caregiver (Phillips, de Ardon, Komnenich, Killeen, & Rusinak, 2000). Further, familismo may be a protective factor as other family members may be more likely to support the primary caregiver.

Marianismo and Machismo

Women are more likely to become an informal caregiver than men are, especially in Latin American cultures (Escandón, 2006; Jolicoeur & Madden, 2002; Maldonado, 2017). This

may be in part due to the cultural norms of *machismo* and *marianismo*, two traditional gender roles in Latin America. Marianismo is a traditional gender role for women in Latin American families (Gutmann, 1997) which influences normative behaviors of submission, reservation, weakness, virginity, and femininity (Mendez-Luck & Anthony, 2016). Given that marianismo encompasses a sense of responsibility to one's family and submissiveness to a woman's male spouse (Hubbell, 1993), it has been postulated that marianismo contributes to the sense of duty to care for family members (Mendez-Luck & Anthony, 2016). This may be particularly relevant for PD caregiving as most individuals with PD are men (Van Den Eeden et al., 2003), which would suggest that there may be a higher proportion of female caregivers in Latin America compared to other geographic regions due to the prevalence of spousal caregiving.

In Latin America, male identity is heavily influenced by machismo (Villarruel, 1995). The values associated with machismo dictate that men should be courageous, brave, the head of the family, and the unquestioned authority figure in the household (Caudle, 1986; Urrabazo 1985; Zoucha, 1997). Research on intergenerational caregiving suggests that male family members are more likely to provide instrumental support (e.g., driving another family member to a health care appointment), while female family members are more likely to provide emotional support and comfort (Ruiz & Ransford, 2012).

Religiosity

The majority of individuals residing in Mexico self-identify as Catholic (Gutiérrez Zúñiga & De La Torre Castellanos, 2017), and the religion has influenced the cultural context of the region which has a number of implications for caregiving. First, within fundamentalist Catholicism, disability and illness may be perceived to be the will of God, which may encourage family members to provide care out of reverence for religious practices that encourage caring for

individuals with illnesses (Rehm, 1999). In addition, there are also influences of marianismo that are associated with Catholicism. For example, In Mexico, the Virgin Mary is a frequent cultural icon and an ideal of a mother figure who is nurturing, obedient to God, virginal, and responsible for her family (Santana & Santana, 2001; Stevens, 1973).

There is also evidence suggesting that religiosity may positively influence how caregivers feel about their roles, particularly among Hispanic caregivers. For example, Epps (2015) found a positive association between positive appraisals of providing care and organizational religiosity among Hispanic individuals, which was not present among African American or Caucasian family caregivers of older adults. Further, Barber (2014) found that among Mexican-American caregivers, prayer and/or meditation predicted perceiving benefits of caregiving, while participation in religious activities and services was associated with lower subjective burden. As such, it is possible that the cultural importance of religion may influence the experiences and subjective feelings regarding caregiving among individuals in Latin America.

Stigma

Although there have been no studies examining PD stigma in Latin America, there are a number of studies that have examined stigma related to PD in other geographic regions. Stigma is critical and influences health-related quality of life (Ma, Saint-Hilaire, Thomas, & Tickle-Degnen, 2016) and it is also associated with depression among individuals with PD (Salazar et al., 2018). Further, experiences with PD stigma may affect the caregiver. For example, Mshana, Dotchin, and Walker (2011) found that in rural areas of Tanzania the entire family of individuals with PD is stigmatized due to their condition. In Europe, at least one study has found that families may be forced to withdraw from social contexts, particularly during meals given

difficulties inviting guests (Miller, Noble, Jones, & Burn, 2006) and handling the visible symptoms of the individual with PD (Chiong-Rivero et al., 2011).

Individuals with disabilities may face stigma in Latin America, which may be associated with cultural values such as religiosity. For example, Espínola-Nadurille, Crail-Melendez, & Sánchez-Guzmán (2014) note that lay cultural explanations of disease may revolve around the concept of divine punishment and supernatural forces. In their sample of individuals living with epilepsy in Mexico, participants reported losing social contacts and experiencing rejection when attempting to establish new social connections. Further, participants' treatment was largely focused on pharmacological interventions for seizure control while health care providers did not address family and social interactions. Given that the motor symptoms of PD may be visible to others, similar to epileptic seizures, it is possible that individuals with PD are also experiencing social isolation from society and social rejection.

It is difficult to draw comparisons of social isolation and community integration of individuals with PD and their families between the North American and Latin American cultural contexts given the lack of research in Latin America. In Latin America, stigma may interact with religiosity and potentially other cultural values such as familismo. For example, familismo may serve as a protective factor in that it encourages family cohesion, which may provide at least one social outlet for caregivers and individuals living with PD.

Parkinson's Disease Literature in Mexico

Overall, there is a very limited amount of research that examines individuals living with PD and their caregivers in Latin America. Given the potentially deleterious outcomes associated with caregiving for an individual living with PD (e.g., caregiver burden) and the rapidly aging population of Latin America, this is a critical gap in the literature. Although there are few studies

that have examined PD in Latin America, what little research has been published has generally been based in Mexico. To date, research examining individuals living with PD has examined prevalence of non-motor symptoms, such as ICDs (Mayela Rodríguez-Violante, González-Latapi, Cervantes-Arriaga, Camacho-Ordoñez, & Weintraub, 2014), depression, (Mayela Rodríguez-Violante, Cervantes-Arriaga, Berlanga-Flores, & Ruiz-Chow, 2012), apathy (Mayela Rodríguez-Violante, González-Latapi, Cervantes-Arriaga, Martínez-Ramírez, et al., 2014), as well as motor dysfunction (Eisinger, Cervantes-Arriaga, Rodriguez-Violante, & Martinez-Ramirez, 2018). Only two studies have included caregivers, which have examined non-motor symptoms and their association with quality of life (Estrada-Bellmann, Camara-Lemarroy, Calderon-Hernandez, Rocha-Anaya, & Villareal-Velazquez, 2016), and factors that influence functional dependence (Quintanar-Llanas et al., 2016).

Despite the importance of informal caregivers and the cultural values that may promote providing informal care in Mexico (i.e., *familismo* and traditional gender roles), a review of the literature only recovered one study that has examined the associations between PD-related impairments and caregiver burden in individuals living with PD. In the study, Rodríguez-Violante, Camacho-Ordoñez, Cervantes-Arriaga, González-Latapí, and Velázquez-Osuna (2015) examined a sample of 250 individuals living with PD and 201 caregivers. Research staff administered questionnaires assessing motor and non-motor symptoms and disease severity, while caregivers self-reported their levels of burden. Although the study examined disease severity as well as both motor and non-motor symptoms of PD, the researchers found that only non-motor impairments significantly predicted caregiver burden in the sample. Interestingly, as noted previously in the current review, motor impairments and disease severity have been consistently associated with caregiver burden (Leiknes et al., 2015). It is unclear why the results

in the Rodriguez-Violante et al. (2015) study may differ from the wide literature base in this area.

To date, there are currently no cross-cultural comparisons of Mexican PD caregivers and caregivers in other regions of the world. Therefore, it is currently unknown if outcomes in Mexican PD informal caregivers are similar or different from caregivers in other regions of the world (e.g., the US) or even within Latin America.

Statement of the Problem

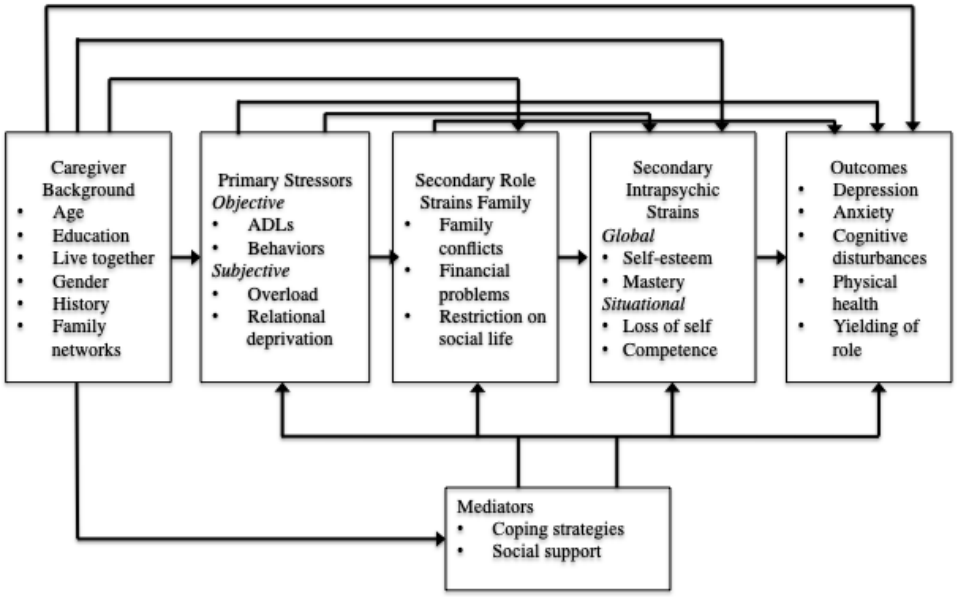
As PD is a progressive, incurable disease, individuals living with PD are often likely to require the assistance of a caregiver, the majority of which are family members. Given the rapidly aging population in both the US (Marras et al., 2018) and Mexico (Cantu-Martinez et al., 2014), rates of PD are likely to rise in both countries, suggesting that the number of individuals providing informal care will also increase.

Similar to individuals living with PD in the US, individuals in Latin America often rely on informal caregiving provided by family members. Reliance on family members may be more frequent in Latin America in part to sociocultural values such as *familismo*. Overall, there are very few studies that have examined PD in any capacity in Latin America, and only a small number have examined the effects of caregiving for individuals living with PD. Further, there have been no known cross-cultural examinations of PD caregiving between the US and Latin America.

The proposed theoretical model for the current study is informed by Pearlin's caregiving stress process model (Pearlin, Lieberman, Menaghan, & Mullan, 1981; Pearlin, Mullan, Semple, & Skaff, 1990). Pearlin's model consists of four domains of caregiving-related stressors: context of the caregiving situation (e.g., caregiver socioeconomic status, age, relationship with the

individual requiring care), primary (e.g., impairments in the individual requiring care) and secondary stressors (e.g., changes in the caregiver's self-concept, family conflict), mediators of stressors (e.g., social support), and caregiver outcomes (e.g., physical and mental health; Pearlin et al., 1990), all of which may interact and influence one another.

Figure 1. Pearlin's caregiving stress process model (Pearlin et al., 1990)



As discussed, prior research has demonstrated a relation between PD-related impairments and caregiver burden. Although there are no causal studies that demonstrate PD-related impairments directly cause caregiver burden, it is plausible that impairments lead to burden and not vice versa. As such, PD-related impairments will serve to predict caregiver burden in the proposed theoretical model. Similarly, PD-related impairments have been associated with reduced mental health among caregivers and will serve as a predictor of mental health in the proposed model. In addition, there is support demonstrating a relation between caregiver burden and caregiver mental health, such that increased levels of caregiver burden are associated with reduced mental health among caregivers. Although the research in this area is cross-sectional, there is some evidence to support that burden may predict mental health, despite the relationship

likely having some reciprocal elements (Mosley et al., 2017). As prior research has found that higher quality relationships between the caregiver and the individual they provide care for have less burden and greater quality of life (Goldsworthy & Knowles, 2008), there is evidence to suggest that family dynamics may serve to buffer the negative aspects of caregiving, such as burden and mental health. As such, family dynamics may serve as a moderator such that healthier family dynamics may correspond to better outcomes among caregivers (e.g., caregiver burden and mental health).

Although research in the US and Europe has generally been able to demonstrate the connections among PD-related impairments, burden, mental health, and family dynamics, this research has yet to be extended to Latin America. Therefore, the current study will use pieces of Pearlin's caregiving stress process model to examine the following relations: (a) PD-related impairments (primary stressor) and mental health (caregiver outcome) potentially through caregiver burden (caregiver outcome); and (d) family dynamics (secondary stressor), which may moderate the previously outlined relations in a sample consisting of caregivers of individuals living with PD from the US and Mexico. The current study hypothesizes the following:

Hypothesis 1: There will be significant mean differences in caregiver burden and mental health and family dynamics between the US and Mexico sites. Given reduced access to specialized PD treatments in Mexico, it is hypothesized that caregivers at the Mexico site will report higher levels of burden and worse mental health and family dynamics than caregivers at the United States site. Alternatively, it is possible that caregivers at the United States site will report higher levels of burden due to a difference in cultural values, such as familismo.

Hypothesis 2: Caregiver burden will mediate the association between PD-related impairments and mental health.

Hypothesis 3: Family dynamics will moderate the meditational model outlined in hypothesis 2 such that healthy family dynamics will reduce (buffer) this mediational effect. Research has yet to examine family dynamics as a potential buffer. However, Pearlin's (1990) model suggests that primary stressors including reduced patient functioning are associated with reduced mental health in caregivers. Additional secondary stressors, including family dynamics, are likely to be associated with both patient impairment as well as mental health. Prior research also suggests that the quality of the caregiver-recipient relationship may buffer caregiver burden and improve quality of life (Goldsworthy & Knowles, 2008).

Hypothesis 4: Family dynamics will be a stronger buffer for the Mexico site compared to the United States site due to traditional cultural values including *familismo* (Zea et al., 1994) that may influence caregiving processes in Mexico. To date, there have been no cross-cultural comparisons of PD caregivers between the United States and Mexico.

Exploratory Analyses: A *t*-test will analyze potential differences in suicidal or self-injurious thoughts among caregivers between the United States and Mexico.

Given cultural values that may promote caregiving among women in Latin America (e.g., familismo, marianismo), a chi-square analysis will analyze potential gender differences in caregiving between the United States and Mexico.

Implications

Results of the current study will serve to inform the PD caregiving literature. Specifically, it will illuminate specific relations among PD-related impairments, caregiver burden and mental health, and family dynamics. Further, the study will also serve to expand the literature on PD in Latin America, which is currently under researched. Finally, the results of the

current study mays serve to identify important clinical targets for caregivers of individuals living with PD.

Method

Participants

This study used cross-sectional data that collected from caregivers of individuals with PD from the Hospital Civil de Guadalajara in Guadalajara, Mexico and the Parkinson's and Movement Disorders Center (PMDC) at Virginia Commonwealth University in Henrico, Virginia. Both centers offer interdisciplinary models of health care for patients as well as services for caregivers. The Hospital Civil de Guadalajara also offers education programs and emotional support groups led by psychologists and lodging and food support for caregivers. To be eligible for this study, participants had to have met the following inclusion criteria: (a) identify as a caregiver of an individual diagnosed with PD, (b) be at least 18 years of age, and (c) be fluent in either English (for the United States site) or Spanish (for the Mexico site).

The demographic characteristics of the caregiver sample are described in Table 1. In the United States sample (N = 105), the majority of caregivers self-identified as women (68.6%). Caregivers had a mean age of 68.73 (SD = 8.36) and were predominantly spouses or partners (93.3%) of individuals with PD. On average, caregivers had provided care for 49.05 months and 60.43 hours per week. The majority of individuals self-identified as White/European American (92.4%), followed by Asian/Asian-American/Pacific Islander (2.9%), Black/African-American (non-Latino; 2.9%), multiracial/multiethnic (1.0%), or other identity (1.0%). Of the sample, 25.7% had a high school education or equivalent, 2-year technical degree (11.4%), 4-year college degree (33.3%), master's degree (21.9%), or doctorate degree (7.6%).

In the Mexico sample (N = 148), the majority of caregivers self-identified as women (76.4%) and had a mean age of 53.66 (SD = 14.96). Over half of the caregivers were spouses or

partners of the individual living with PD (51.4%). On average, caregivers provided care for 52.38 (*SD* = 49.22) months and 107.39 (*SD* = 61.34) hours per week. Information on race/ethnicity was not collected for the Mexico site because it was not applicable. Of the sample, 4.7% had no formal education, 58.1% had an elementary school education, 5.4% had a high school education or equivalent, 13.5% had a 2-year technical degree, 16.2% had a 4-year college degree, and 2.0% had a master's degree.

Table 1. *Characteristics of PD Caregivers (N = 253)*

Demographic Variable	Value	
	United States	Mexico
Age, years, mean (SD)	68.73 (8.36)	53.66 (14.96)
Sex, %		
Female	68.6%	76.4%
Male	31.4%	23.6%
Relationship status		
Married or partnered	96.2%	77.7%
Single	1.0%	17.6%
Widowed	0%	.7%
Divorced or separated	2.9%	4.1%
Relationship to individual with PD, %		
Parent	3.8%	34.5%
Aunt/Uncle	1.0%	1.4%
Spouse/romantic partner	93.3%	51.4%
Sibling	0%	7.4%
Child	0%	0%
Friend	1.9%	.7%
Professional caregiver	0%	0%
Cousin	0%	.7%
Other	0%	4.1%
Number of individuals who assist in providing care, mean (SD)	.46 (1.08)	.62 (.88)
Months providing care, mean (SD)	49.05 (80.48)	52.38 (49.22)
Hours per week of care, mean (SD)	60.43 (63.53)	107.39 (61.34)
Current occupation (%)		
Homemaker (Mexico only)	0%	14.2%
Full-time employment	16.2%	12.2%
Part-time employment	8.6%	28.4%
Student	0%	.7%
Unemployed	5.7%	22.3%
Retired	64.8%	6.1%
Other	4.8%	16.2%

T-tests and chi-square analyses were used to examine potential demographic differences between sites. Caregivers at the United States site were significantly older than those at the Mexico site, $t(251) = 9.335$, $p < .001$. There were no differences between sites in length of time (in months) providing care, $t(251) = -.408$ $p = .648$. However, caregivers at the Mexico site spent significantly more hours per week providing care than those at the United States site, $t(251) = -5.913$, $p < .001$. Finally, there were no differences in the number of individuals who assist the caregiver in providing care, $t(251) = -1.327$, $p = .186$.

There was a similar gender distribution between sites, $\chi^2 = 1.892$ (1), $p = .169$. There were differences in the caregivers' relationship status, $\chi^2 = 19.305$ (3), $p < .001$ and the caregivers' relationship with the individual living with PD, $\chi^2 = 55.919$ (6), $p < .001$. Finally, there were differences in employment status between sites, $\chi^2 = 115.766$ (6), $p < .001$.

Information on the individual living with PD was also provided by the caregiver and is described in Table 2. Across both sites, the individuals living with PD were predominantly male. In the United States sample, the average age of the individual with PD was 71.61 (*SD* = 8.13) while the average age in the Mexico sample was 65.68 (*SD* = 10.78).

Table 2. *Characteristics of individuals with PD as Reported by Caregivers* (*N* = 253)

Demographic Variable	Value	
	United States	Mexico
Age, years, mean (SD)	71.61 (8.13)	65.68 (10.78)
Sex, %		
Female	35.2%	48.0%
Male	64.8%	52.0%
Months since PD diagnosis, mean (SD)	92.25 (82.84)	63.22 (60.88)

A t-test demonstrated that the individual living with PD was older at the United States site than the Mexico site, $t(251) = 4.762$, $p = .022$. Finally, there was a longer time since

diagnosis for individuals at the United States site compared to the Mexico site, $t(251) = 3.227$, $p = .001$. Finally, there was a significant relation between gender and site, $\chi^2 = 4.072$ (1), $p = .044$.

Measures

Participants completed a number of questionnaires in English (United States site) or Spanish (Mexico site), including demographics, PD-related impairments, caregiver burden, mental health (depression and anxiety), and family dynamics. All study measures including depression (Diez-Quevedo, Rangil, Sanchez-Planell, Kroenke, & Spitzer, 2001; Donlan & Lee, 2010; Wulsin, Somoza, & Heck, 2002), anxiety (García-Campayo et al., 2010), caregiver burden (Marín, 1996), and PD-related impairments (Martinez-Martin et al., 2013) were previously translated into and validated in Spanish. The family dynamics measure has previously been translated into Spanish (Association for Family Therapy & Systematic Practice, n.d.) although the translated version has not been validated.

Demographic information. Participants provided their age, gender, race/ethnicity (at the U.S. site), education, current employment status, if they receive assistance caring for the patient, relationship to the individual with PD, relationship status, hours per week of care provided, how many months of care have been provided, time since the patient's PD diagnosis, and number of individuals who assist the caregiver in providing care.

Anxiety. The Generalized Anxiety Disorder-7 (GAD-7; Spitzer, Kroenke, Williams, & Löwe, 2006) was used to assess anxiety. Participants respond to the 7-item measure on a Likert-type scale from 0 (Not at all) to 3 (Nearly every day). Participants' scores may range from 0 to 21, with higher scores indicating greater levels of anxiety. Total scores in the range from 0 to 4 correspond to minimal anxiety severity, 5 to 9 corresponds to mild anxiety severity, 10 to 14 moderate severity, and scores from 15 to 21 correspond to severe anxiety severity. The GAD-7

has previously been translated and validated in Spanish and demonstrated excellent internal consistency (α = .92; García-Campayo et al., 2010). In the current study, the GAD-7 demonstrated good internal consistency in the Mexico (α = .88) and the United States sample (α = .90).

Caregiver burden. The short version of the Zarit Burden Inventory (Bédard et al., 2001) was used to assess caregiver burden. Participants respond to the 12-item version of the ZBI on a Likert-type scale from 0 (Never) to 4 (Nearly Always), where higher scores indicate higher levels of caregiver burden. Scores from each item are combined to create a total score that may range from 0 to 48. A total score in the range of 0 to 20 corresponds to little or no caregiver burden. A total score in the range of 21 to 40 corresponds to mild to moderate burden, while a total score of 61 to 88 corresponds to severe caregiver burden. The full version of the ZBI has previously been validated in caregivers of individuals living with Parkinson's disease (Martínez-Martín et al., 2007). The ZBI has also been validated in Spanish-speaking individuals and demonstrated good internal consistency (α = .92; Marín, 1996). In the current study, the measure demonstrated good internal consistency in the Mexico (α = .86) and the United States sample (α = .91).

Depression. The Patient Health Questionnaire-9 (PHQ-9; Kroenke, Spitzer, & Williams, 2001) was used to assess depressive symptomatology. Participants respond to the 9-item measure on a Likert-type scale from 0 (Not at all) to 3 (Nearly every day), where higher scores correspond to greater depressive symptomatology. Scores from each item are combined to create a total score that may range from 0 to 27. A total score in the range of 0 to 4 corresponds to no depressive symptomatology. A total score in the range of 5 to 9 corresponds to mild depressive symptomatology, 10 to 14 corresponds to moderate depressive symptomatology, 15 to 19

corresponds to moderately severe depressive symptomology, and scores in the range from 20 to 27 correspond to severe depressive symptomatology. The PHQ-9 has previously been validated in Spanish-speaking individuals and demonstrated good internal consistency (α = .92; (Diez-Quevedo et al., 2001; Donlan & Lee, 2010; Wulsin et al., 2002). In the current study, the PHQ-9 demonstrated good internal consistency in the Mexico (α = .81) and the United States sample (α = .82).

Family dynamics. Family dynamics was assessed by the SCORE-15 (Stratton, Bland, Janes, & Lask, 2010). Participants respond to the 15-item measure on a Likert-type scale ranging from 1 (Describes us: very well) to 5 (Describes us: not at all). The SCORE-15 consists of three subscales (strengths and adaptability, overwhelmed by difficulties, and disrupted communication) as well as a total score that is created by summing each item of the measure. The overwhelmed by difficulties and disrupted communication subscales were reverse-scored in the current study so that higher scores correspond to healthier family dynamics. Total scores range from 15 to 75 with higher scores corresponding to better family functioning. Overall, the SCORE-15 has demonstrated good internal consistency (α = .89; Stratton, Bland, Janes, & Lask, 2010). This measure has previously been translated into Spanish (Association for Family Therapy & Systematic Practice, n.d.) although it has not been validated in Spanish.

In the current study, the total SCORE-15 demonstrated good internal consistency in the Mexico (α = .86) and the United States samples (α = .89). The struggling to adapt subscale demonstrated acceptable internal consistency in the Mexico sample (α = .70) and the United States sample (α = .83). Similarly, the overwhelmed by difficulties subscale demonstrated acceptable internal consistency in the Mexico sample (α = .78) and the United States sample (α = .79). The disrupted communication scale demonstrated borderline acceptable internal

consistency in the Mexico sample (α = .64) and acceptable internal consistency in the United States sample (α = .73).

An exploratory factor analysis (EFA) using maximum likelihood estimation and promax rotation was conducted to analyze the structure of the measure in the Mexico sample. Although the results of the EFA suggested a four-factor solution explaining 59.27% of the variance, results suggested the model did not fit well and items did not demonstrate simple structure. As such, the total score for the family dynamics will be used for hypotheses 3 and 4.

PD Impairments. PD-related impairments were assessed using the Movement Disorder Society – Unified Parkinson's Disease Rating Scale (MDS-UPDRS; Goetz et al., 2008). Participants in the current study were instructed to answer this questionnaire based on their observations and experiences with the individual living with PD. Participants responded to two subscales within the questionnaire: Part I (non-motor experiences of daily living) and Part II (motor experiences of daily living). Participants respond to each item on a Likert-type scale that ranges from 0 (Normal: No problems present) to 4 (Severe: Problems are present and preclude the patient's ability to carry out normal activities or social interactions or to maintain previous standards in personal or family life). In the present study, total scores for each subscale were created by summing scores for each item within the subscale. The non-motor experiences of daily living subscale has acceptable internal consistency (α = .79) and the motor experiences of daily living has good internal consistency (α = .90; (Goetz et al., 2008). The Movement Disorder Society (MDS) has also translated and validated the scale in Spanish, with the non-motor experiences of daily living demonstrating acceptable internal consistency (α = .79) and the motor experiences of daily living demonstrating good internal consistency (α = .92) (Martinez-Martin et al., 2013). In the current study, the non-motor subscale demonstrated good internal

consistency in the Mexico (α = .80) and the United States sample (α = .85). The motor subscale demonstrated good internal consistency in the Mexico (α = .88) and the United States sample (α = .90).

Procedure

The protocol for the current study was reviewed and approved by the Institutional Review Boards at both data collection sites, Virginia Commonwealth University and the Hospital Civil De Guadalajara. Participants were recruited by study staff (i.e., research assistants) at both sites using written and verbal advertisements, predominantly from waiting rooms but also via clinician referral after medical appointments. Email advertisements were also sent to a listserv at the PMDC at Virginia Commonwealth University. At each data collection location, interested individuals were provided with information on the study in the respective clinic and provided informed consent prior to enrolling in the study. Participants were then screened for eligibility, and if eligible, completed all study measures. The protocol was orally administered at the Hospital Civil De Guadalajara site to collect demographic and questionnaire data in order to account for higher rates of illiteracy than at the U.S. site. The oral interview took approximately an hour. Participants from the PMDC completed all survey measures independently using pencil and paper. Completion of study measures took participants approximately the same amount of time.

Data Analysis

Power Analysis. A post-hoc power analysis was conducted for each site to compute achieved power using G*Power 3 (Faul, Erdfelder, Lang, & Buchner, 2007). A medium effect size was specified (Cohen's f^2 = .15) with an alpha level of .05 for both sites for the five predictors in the current study (the largest power requirement in the PROCESS macro which will

be used for hypotheses 2-4; Hayes, 2017). For the Mexico site (N = 148) the power was .99. For the United States site (N = 105) the power was .98. Overall, this suggests that there was adequate statistical power to test the study hypotheses.

Preliminary analyses. Frequencies and descriptive statistics for PD-related impairments, caregiver burden, family dynamics, and mental health were run before testing study hypotheses. To compute the mental health variable, the z-scores for the depression and anxiety scales were combined. Subsequently, bivariate associations were analyzed in a correlation matrix consisting of PD-related impairments, caregiver burden, mental health, and family dynamics, as well as a correlation matrix examining study variables and caregiver demographic characteristics.

Hypothesis testing. An independent-samples *t*-test was conducted to determine if there were significant differences in caregiver burden (personal and role strain), caregiver mental health (depression and anxiety), and family dynamics (struggling to adapt, disrupted communication, overwhelmed by difficulties) between sites. An independent samples *t*-test was also used to analyze potential differences in suicidal or self-injurious thoughts between sites. Finally, a chi-square test was run to analyze potential differences in gender of the caregiver between sites.

Four mediation models (Figures 1, 2) were created to determine if caregiver burden mediates the relationship between PD-related impairments and caregiver mental health. Specifically, the first model used motor impairments as a predictor and a second model used non-motor impairments as a predictor. Each of these models were run separately by site for a total of four mediation models. The PROCESS macro (Hayes, 2017) will be used to test each of the mediation models. This macro utilizes Preacher and Hayes (2004; 2008) asymptotic bootstrapping approach. Preacher and Hayes (2004; 2008) developed this approach as the *ab*

sampling distribution can be non-symmetric and non-normal. Therefore, instead of assuming the distribution is symmetrical and normal, a bootstrapping approach is used to create the sampling distribution. In this approach, a large number of samples are taken from the data, and by sampling with replacement, the indirect effect from each sample is calculated. For the proposed analysis, a sample of 5,000 bootstrap samples will be taken as recommended by Preacher and Hayes (2004; 2008). The indirect effect estimate will be calculated by taking the mean of all of the indirect effects across the bootstrap samples. In this approach, statistical significance is determined by creating a confidence interval surrounding the indirect effect. The proposed analysis will use a 95% confidence interval with an α level of .05. The null hypothesis will be rejected (i.e., there is no indirect effect) if the obtained confidence interval does not contain zero. All predictor variables (motor and non-motor impairments, caregiver burden) were mean-centered prior to running analyses.

Figure 2. Proposed mediation model with motor impairments as a predictor

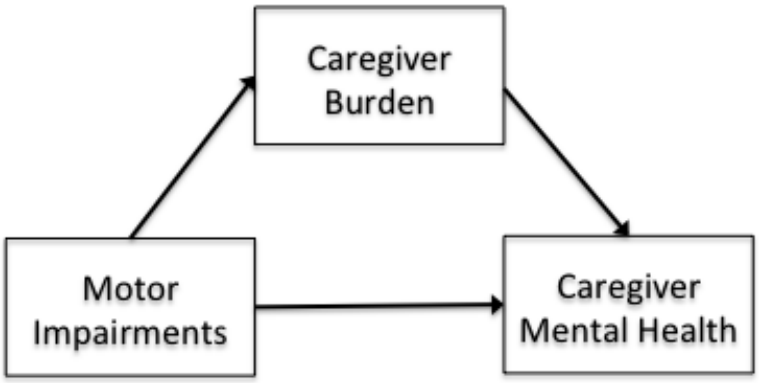
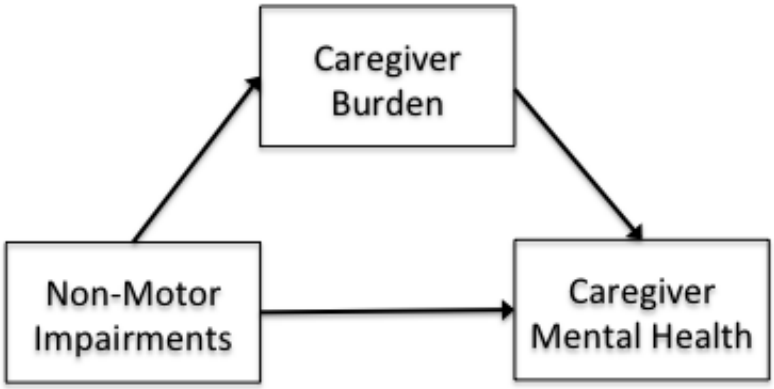


Figure 3. Proposed mediation model with non-motor impairments as a predictor



Then, conditional process analyses (i.e., moderated mediations; Figure 3) were conducted to determine if the mediation models vary by levels of family dynamics. Specifically, it was hypothesized that family dynamics would explain more overall variance in the moderated mediation at the Mexico site. Again, one model used motor symptoms as a predictor while the second model used non-motor symptoms as a predictor. The proposed analyses used a 95% confidence interval with an α level of .05 and the null hypothesis will be rejected (i.e., there is no moderated mediation) if the confidence interval does not contain zero.

Figure 4. Proposed conditional process analysis (i.e., moderated mediation model) with motor impairments as a predictor

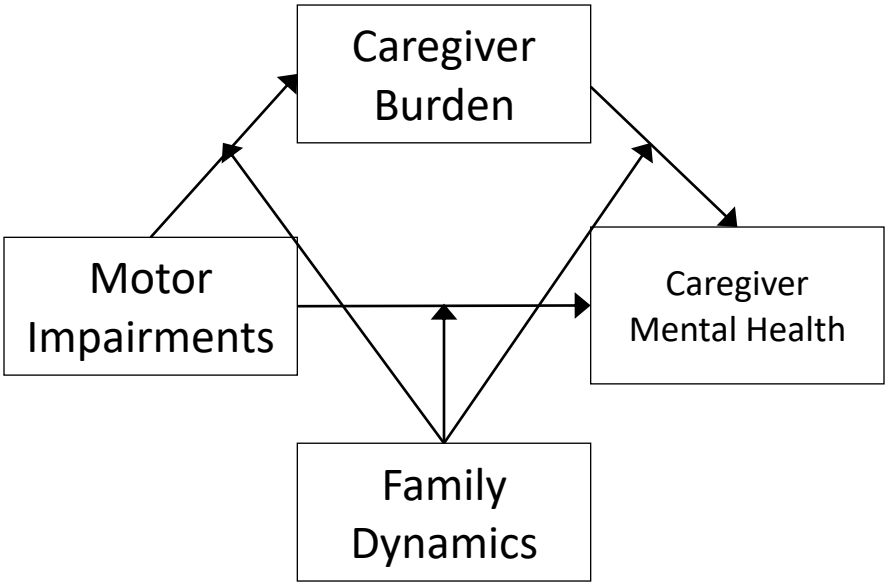
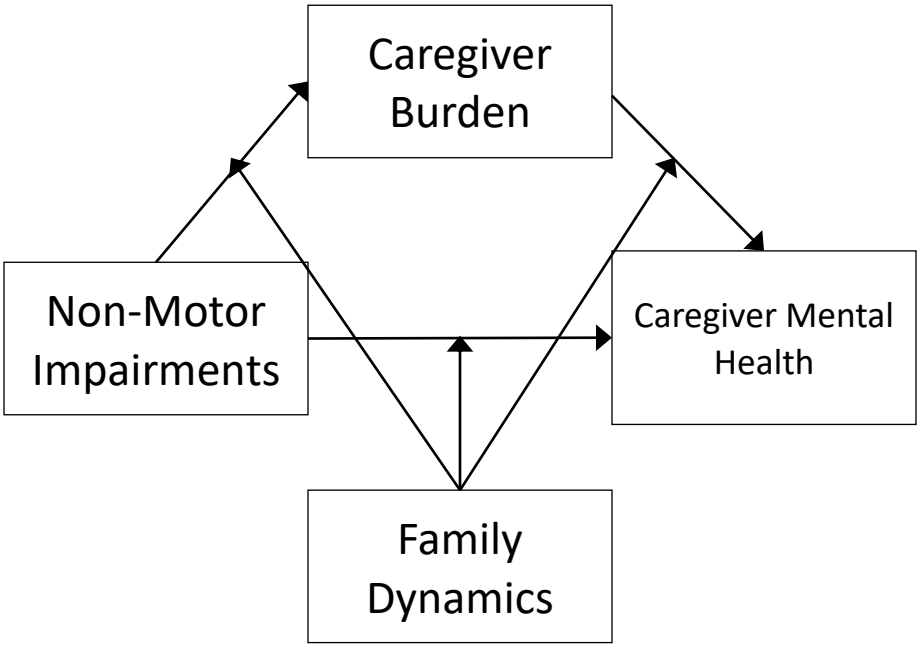


Figure 5. Proposed conditional process analysis (i.e., moderated mediation model) with non-motor impairments as a predictor



Results

Missing Data

One participant's data from the original sample size of 254 was removed due to inconsistent responding (selecting the same value for every item irrespective of directional coding). Additional missing data points were addressed using expectation maximization in SPSS 24 (IBM Corp., 2016). In the current study, only nine variables contained missing data (<1% of participants for each variable). Little's missing completely at random (MCAR) test was used to determine whether data were missing at random, and results suggest that data were missing completely at random, $\chi^2 = 85.10$ (103), $p = .900$.

Normality

Prior to running analyses, normality assumptions were examined. None of the study measures met the criteria for skewness (absolute value of 2.0), although both anxiety (2.042) and

depression (2.746) met the criteria for kurtosis. Because of these minor departures from normality, the data were retained in their raw form.

Outliers

Each continuous variable was also screened for univariate outliers. Non-motor symptoms had two outliers (*z*s = 3.277, 3.04), motor symptoms had two outliers (*z*s = 3.43, 3.33), personal strain had two outliers (*z*s = 3.07, 3.07), role strain had one outlier (*z*s = 3.36), anxiety had four outliers (*z*s = 3.82, 3.13, 3.13, 3.13), depression had five outliers (*z*s = 4.08, 3.84, 3.84, 3.60, 3.11), overwhelmed by difficulties had three outliers (*z*s = |3.29|, |3.05|, |3.05|), and disrupted communication had two outliers (*z*s = |3.71|, |3.16|). All univariate outliers were marginal (*z*s < 4.08) and were unchanged.

Summary of Outcome Variables

PD-Related Impairments. Descriptive statistics and frequency distributions were calculated to analyze caregiver-reported PD-related impairments (Table 3, Table 4).

Table 3. *Summary of PD-Related Impairments Reported by Caregivers (N = 253)*

Variable	Site	
	United States	Mexico
	Mean (SD)	Mean (SD)
Motor Symptoms	28.98 (9.89)	27.51 (9.31)
Non-Motor Symptoms	27.79 (8.28)	26.45 (8.17)

A summary of PD-related impairments by symptom category and site is listed in Table 4. Independent samples *t*-tests were conducted to analyze differences between sites. There were no significant differences between caregiver-reported motor symptoms between sites, $t(251) = 1.208$, $p = .228$. Similarly, there were no differences between caregiver-reported non-motor symptoms between sites, $t(251) = 1.275$, $p = .204$.

Table 4. *Summary of Symptoms Reported by Caregivers (N = 253)*

Symptom Domain	Symptom Endorsed	% Endorsing Symptom	
		United States	Mexico
Motor	Speech		
	Normal	24.8%	38.5%
	Slight	19.0%	25.7%
	Mild	29.5%	16.9%
	Moderate	23.8%	12.8%
	Severe	2.9%	6.1%
	Saliva/Drooling		
	Normal	57.1%	60.8%
	Slight	12.4%	13.5%
	Mild	11.4%	16.2%
	Moderate	9.5%	8.1%
	Severe	9.5%	1.4%
	Chewing and Swallowing		
	Normal	55.2%	72.3%
	Slight	36.2%	10.8%
	Mild	6.7%	10.8%
	Moderate	1.0%	4.7%
	Severe	0.0%	1.4%
	Eating Tasks		
	Normal	45.7%	43.2%
	Slight	28.6%	33.1%
	Mild	21.9%	16.2%
	Moderate	2.9%	6.8%
	Severe	1.0%	.7%
	Dressing		
	Normal	28.6%	22.3%
	Slight	21.0%	52.0%
	Mild	37.1%	15.5%
	Moderate	7.6%	7.4%
	Severe	5.7%	2.7%
	Hygiene		
	Normal	42.9%	27.7%
	Slight	31.4%	49.3%
	Mild	17.1%	15.5%
	Moderate	4.8%	4.1%
	Severe	3.8%	3.4%

Handwriting		
Normal	22.9%	31.8%
Slight	25.7%	33.8%
Mild	22.9%	14.9%
Moderate	21.0%	11.5%
Severe	7.6%	8.1%
Hobbies and Other Activities		
Normal	27.6%	27.7%
Slight	20.0%	21.6%
Mild	25.7%	15.5%
Moderate	17.1%	23.0%
Severe	9.5%	12.2%
Turning in Bed		
Normal	38.1%	37.2%
Slight	41.9%	35.8%
Mild	12.4%	16.2%
Moderate	5.7%	7.4%
Severe	1.9%	3.4%
Tremor		
Normal	26.7%	18.9%
Slight	46.7%	44.6%
Mild	18.1%	18.2%
Moderate	6.7%	14.2%
Severe	1.9%	4.1%
Getting out of Bed, Car, or Deep Chair		
Normal	14.3%	31.1%
Slight	34.3%	28.4%
Mild	29.5%	25.0%
Moderate	15.2%	10.8%
Severe	6.7%	4.7%
Walking and Balancing		
Normal	14.3%	23.6%
Slight	42.0%	39.9%
Mild	14.3%	16.2%
Moderate	24.8%	15.5%
Severe	4.8%	4.7%
Freezing		
Normal	52.4%	60.8%

	Slight	20.0%	18.9%
	Mild	6.7%	6.8%
	Moderate	15.2%	8.8%
	Severe	5.7%	4.7%
Non-Motor	Cognitive Impairment		
	Normal	26.7%	39.2%
	Slight	27.6%	29.1%
	Mild	17.1%	15.5%
	Moderate	23.8%	11.5%
	Severe	4.8%	4.7%
	Hallucinations and Psychosis		
	Normal	78.1%	82.4%
	Slight	12.4%	9.5%
	Mild	5.7%	4.1%
	Moderate	2.9%	2.7%
	Severe	1.0%	1.4%
	Depressed Mood		
	Normal	37.1%	33.1%
	Slight	41.0%	24.3%
	Mild	11.4%	17.6%
	Moderate	8.6%	20.3%
	Severe	1.9%	4.7%
	Anxious Mood		
	Normal	36.2%	31.3%
	Slight	38.1%	31.8%
	Mild	17.1%	16.2%
	Moderate	6.7%	18.2%
	Severe	1.9%	2.7%
	Apathy		
	Normal	39.0%	56.1%
	Slight	35.2%	17.6%
	Mild	18.1%	13.5%
	Moderate	3.8%	10.5%
	Severe	3.8%	2.7%
	Dopamine Dysregulation Syndrome		
	Normal	68.6%	79.1%
	Slight	16.2%	8.1%
	Mild	11.4%	5.4%

Moderate	3.8%	4.7%
Severe	0.0%	2.7%
Sleep Problems		
Normal	19.0%	33.1%
Slight	22.9%	20.9%
Mild	27.6%	16.9%
Moderate	23.8%	19.6%
Severe	5.7%	9.5%
Daytime Sleepiness		
Normal	14.3%	29.1%
Slight	24.8%	25.0%
Mild	51.5%	25.0%
Moderate	6.7%	16.9%
Severe	2.9%	4.1%
Pain and Other Sensations		
Normal	21.9%	30.4%
Slight	36.2%	31.3%
Mild	15.3%	21.6%
Moderate	16.2%	14.2%
Severe	10.5%	2.7%
Urinary Problems		
Normal	38.1%	54.1%
Slight	26.7%	23.0%
Mild	15.2%	10.1%
Moderate	13.3%	9.5%
Severe	6.7%	3.4%
Constipation		
Normal	33.3%	43.2%
Slight	37.1%	23.0%
Mild	16.2%	18.9%
Moderate	13.3%	12.8%
Severe	0.0%	2.0%
Lightheadedness on standing		
Normal	52.4%	65.5%
Slight	27.6%	19.6%
Mild	10.5%	5.4%
Moderate	9.5%	8.1%
Severe	0.0%	1.4%
Fatigue		

Normal	18.1%	34.5%
Slight	41.0%	27.7%
Mild	25.7%	18.2%
Moderate	10.5%	14.2%
Severe	4.8%	5.4%

Caregiver Burden. Descriptive statistics and frequency distributions were calculated to analyze self-reported caregiver burden. Mean scores for caregiver burden are listed in Table 5. Participant total scores on the ZBI had a range from 0 to 36 out of a possible total score of 48. Potential differences in scores between sites are explored in the Hypothesis Testing section.

Table 5. *Summary of Caregiver Burden Outcomes (N = 253)*

Variable	Value, mean (SD)	
	United States	Mexico
ZBI Total Score	14.52 (8.37)	8.98 (8.12)
Personal Strain	10.30 (6.85)	6.30 (7.00)
Role Strain	4.22 (2.39)	2.68 (2.54)

Caregiver Mental Health. Descriptive statistics and frequency distributions were calculated for each caregiver mental health construct (i.e., depression and anxiety). Mean scores and number of participants scoring in the clinical range are listed in Table 6. Potential differences in scores between sites are explored in the Hypothesis Testing section.

Table 6. *Summary of Caregiver Mental Health Outcomes (N = 253)*

Variable	Value	
	United States	Mexico
PHQ-9 Total Score, mean (SD)	4.00 (3.84)	4.25 (4.34)
Minimal Depression (%)	67.62%	62.84%
Mild Depression (%)	22.86%	25.0%
Moderate Depression (%)	6.66%	8.78%

Moderate-Severe Depression (%)	1.9%	2.03%
Severe Depression (%)	.95%	1.35%
GAD-7 Total Score, mean (SD)	4.30 (4.29)	4.41 (4.42)
Minimal Anxiety (%)	61.90%	65.54%
Mild Anxiety (%)	27.62%	22.97%
Moderate Anxiety (%)	4.76%	6.76%
Severe Anxiety (%)	5.71%	4.73%

Family Dynamics. Descriptive statistics and frequency distributions were calculated for each subscale of the SCORE-15 (Table 7). Potential differences in scores between sites are explored in the Hypothesis Testing section.

Table 7. *Summary of Family Dynamics Outcomes (N = 253)*

Variable	Value, mean (SD)	
	United States	Mexico
SCORE-15 Total Score	62.70 (9.10)	61.65 (9.99)
Struggling to Adapt	20.32 (3.66)	21.16 (3.48)
Overwhelmed by Difficulties	21.15 (3.65)	20.42 (4.51)
Disrupted Communication	21.23 (3.33)	20.06 (3.81)

Bivariate Relationships among Variables

A correlation matrix was created to examine the bivariate relationships among study variables (Table 8). Correlations for the United States site are listed in the top half of the table and correlations for the Mexico site are listed in the bottom half of the table.

Table 8. *Overall correlation matrix of PD-related impairments, caregiver burden and caregiver mental health, and family dynamics separated by site (N = 253)*

	1	2	3	4	5	6	7	8	9
1. Motor Symptoms		.603**	.560**	.221*	0.184	0.155	-.192*	-0.140	-.114
2. Non-Motor Symptoms	.685**		.652**	.385**	.258**	.275**	-.355**	-.216*	-.234*
3. Personal Strain	.375**	.474**		.534**	.434**	.573**	-.488**	-.354**	-.261**
4. Role Strain	0.143	.238**	.294**		.402**	.413**	-.415**	-.327**	-.277*
5. Depression	0.061	.200*	.260**	0.126		.733**	-.349**	-.380**	-.295**
6. Anxiety	0.058	.201*	.245**	-0.004	.615**		-.449**	-.475**	-.324**
7. Struggling to Adapt	-.166*	-.240**	-.351**	-0.135	-.302**	-.176*		.591**	.580**
8. Overwhelmed by Difficulties	-0.056	-.196*	-.337**	-.275**	-.428**	-.275**	.500**		.627**
9. Disrupted Communication	-0.060	-0.156	-.396**	-.170*	-.380**	-.258**	.542**	.661**	

Note. * denotes $p < .05$; **$p < .01$

Overall, the patterns of correlations were generally similar between sites. Significant associations were found between motor symptoms and personal strain at the United States and the Mexico sites ($r = .560$, $p < .01$; $r = .375$, $p < .01$, respectively) as well as between non-motor symptoms and personal strain ($r = .652$, $p < .01$; $r = .474$, $p < .01$). Role strain was associated with motor symptoms at the United States site ($r = .221$, $p < .05$) but not at the Mexico site ($r = .143$, $p = .083$). However, role strain was associated with non-motor symptoms at the United States and the Mexico site ($r = .385$, $p < .01$; $r = .238$, $p < .01$). Motor symptoms were not associated with depression at the United States site or the Mexico site ($r = 184$, $p = .061$; $r = .061$, $p = .458$) or with anxiety ($r = .155$, $p = .113$; $r = .058$, $p = .487$). However, non-motor symptoms were associated with depression at the United States and the Mexico sites ($r = .258$, $p < .01$, $r = .200$, $p < .05$) and were also associated with anxiety ($r = .275$, $p < .01$; $r = .201$, $p < .05$). Of the family dynamics subscales, motor symptoms were only associated with struggling to adapt at the United States and the Mexico site ($r = -.192$ $p < .05$, $r = -.166$, $p < .05$). Non-motor symptoms were associated with struggling to adapt in the United States and Mexico ($r = -.355$, $p < .01$; $r = -.240$, $p < .01$) and overwhelmed by difficulties ($r = -.216$, $p < .05$; $r = -.196$, $p < .05$). Non-motor symptoms were associated with disrupted communication at the United States site ($r = -.234$, $p < .05$) but not at the Mexico site ($r = -.156$, $p = .059$).

Personal strain was associated with depression at the United States and Mexico sites ($r = .434$, $p < .01$; $r = .260$, $p < .01$) and anxiety ($r = .573$, $p < .01$; $r = .245$, $p < .01$). Personal strain was also associated with struggling to adapt ($r = -.488$, $p < .01$; $r = -.351$, $p < .01$), overwhelmed by difficulties ($r = -.354$, $p < .01$; $r = -.337$, $p < .01$), and disrupted communication ($r = -.261$, $p < .01$; $r = -.396$, $p < .01$) at the United States and Mexico sites. Although role strain was not

associated with depression or anxiety at the Mexico site (r = .126, p = .126; r = -.004, p = .959), significant associations were found at the United States site (r = .402, p < .01; r = .413, p < .01). Role strain was also not associated with struggling to adapt at the Mexico site (r = -.135, p = .101) but an association was found at the United States site (r = -.415, p < .01). Role strain was also associated with both overwhelmed by difficulties (r = -.327, p < .01; r = -.275, p < .01) and disrupted communication (r = -.277, p < .05; r = -.170, p < .05) at both sites.

At the United States and Mexico sites, depression was associated with struggling to adapt (r = -.349, p < .01; r = -.302, p < .01), overwhelmed by difficulties (r = -.380, p < .01; r = -.428, p < .01), and disrupted communication (r = -.295, p < .01; r = -.380, p < .01). Similarly, anxiety was associated with struggling to adapt (r = -.449, p < .01; r = -.176, p < .05), overwhelmed by difficulties (r = -.475, p < .01; r = -.275, p < .01), and disrupted communication (r = -.324, p < .01; r = -.258, p < .01).

Another correlation matrix was created to examine the bivariate associations between caregiver (gender, age, education, how many individuals assist with care, care provided [hours per week], and months providing care) and patient demographic variables (gender, age, time since diagnosis) and outcome variables (PD-related impairments, caregiver burden and mental health, and family dynamics; Table 9) by site.

Table 9. *Correlations Between Caregiver Demographics, PD-Related Impairments, Caregiver Burden and Mental Health, and Family Dynamics at the United States site (N = 105)*

Variables	Caregiver Age	Education	Patient Age	How Many Individuals Assist with Care	Care Provided (Hours per Week)	Months Providing Care	Time Since Diagnosis (Months)
Motor Symptoms	.010	.112	.183	.161	.525**	.106	.284**
Non-Motor Symptoms	.048	-.084	.094	.160	.436**	.042	.067
Personal Strain	-.178	.047	-.065	.028	.358**	.056	.085
Role Strain	-.277*	-.073	-.192*	.117	.116	.008	-.026
Depression	-.168	.024	-.198*	-.002	.158	-.033	-.053
Anxiety	-.214	.092	-.211*	-.076	.102	-.039	-.065
Struggling to Adapt	.121	.098	.004	.134	-.009	.062	.096
Overwhelmed by Difficulties	.151	.091	.106	-.013	-.073	-.137	.036
Disrupted Communication	-.004	.105	-.065	-.104	-.073	.170	.173

Note. * denotes $p < .05$; **$p < .01$

Table 10. *Correlations Between Caregiver Demographics, PD-Related Impairments, Caregiver Burden and Mental Health, and Family Dynamics at the Mexico site (N = 148)*

Variables	Caregiver Age	Education	Patient Age	How Many Individuals Assist with Care	Care Provided (Hours per Week)	Months Providing Care	Time Since Diagnosis (Months)
Motor Symptoms	-.015	-.126	.079	-.058	.095	.183*	.191*
Non-Motor Symptoms	-.003	-.108	.165*	.025	.129	.060	.008
Personal Strain	.152	-.057	.100	-.110	.152	.105	-.068
Role Strain	-.154	-.011	.037	.080	-.022	-.119	-.070
Depression	-.148	-.033	-.177*	-.071	.047	-.057	-.137
Anxiety	-.064	-.141	.000	.006	.126	.021	-.100
Struggling to Adapt	.281**	-.009	-.012	.018	.122	-.050	.022
Overwhelmed by Difficulties	.058	.097	-.040	-.096	-.010	.004	.077
Disrupted Communication	.046	.063	.021	-.036	.018	.075	.115

Note. * denotes $p < .05$; **$p < .01$

At the United States site, caregiver age was negatively associated with role strain (r = -.277, p < .05). Age of the individual living with PD was negatively associated with role strain (r = -.192, p < .05), depression (r = -.198, p < .05), and anxiety (r = -.211, p < .05). Amount of care provided (hours per week) was associated with motor symptoms (r = .542, p < .01), non-motor symptoms (r = .451, p < .01), and personal strain (r = .364, p < .01). Time since diagnosis (in months) was associated with motor symptoms (r = .284, p < .01).

At the Mexico site, caregiver age was associated with struggling to adapt (r = .281, p < .01). Age of the individual living with PD was associated with non-motor symptoms (r = .165, p < .05). Similar to the United States site, age of the individual living with PD was associated with depression (r =-.177, p < .05). Length of time providing care (in months) was associated with motor symptoms (r = .183, p < .05). Similar to the United States site, time since diagnosis (in months) was associated with motor symptoms (r = .191, p < .05).

Hypothesis Testing

Hypothesis 1. An independent samples *t*-test was conducted in order to analyze mean differences in caregiver burden (personal and role strain), caregiver mental health (depression and anxiety), and family dynamics (struggling to adapt, overwhelmed by difficulties, and disrupted communication) between sites. Results indicated that there were significant differences in personal strain between caregivers at the United States site (M = 10.30, SD = 6.85) and those at the Mexico site (M = 6.30, SD = 7.00), such that caregivers from the United States reported more personal strain, $t(251) = 4.526$, p < .001. Similarly, results indicated that there were significant differences in levels of role strain, $t(251) = 4.862$, p < .001 between the United States site (M = 4.22, SD = 2.39) and the Mexico site (M = 2.68, SD = 2.54). As such, these results supported the first hypothesis.

Further, there were no significant differences in anxiety between caregivers at the United States site (M = 4.30, SD = 4.30) and the Mexico site (M = 4.41, SD = 4.42), $t(251) = -.180$, $p = .857$. There were also no significant differences in depression between caregivers at the United States site (M = 4.00, SD = 3.84) and the Mexico site (M = 4.25, SD = 4.34), $t(251) = -.473$, $p = .637$, which also did not support the hypothesis.

Finally, there were no significant differences between sites on the struggling to adapt subscale, $t(251) = -1.865$, $p = .063$. There were also no significant differences on the overwhelmed by difficulties subscale, $t(251) = 1.370$, $p = .172$. However, there were significant differences on the disrupted communication subscale, $t(251) = 2.527$, $p = .012$, such that caregivers from the Mexico site (M = 20.06, SD = 3.81) had higher levels of disrupted communication than the United States site (M = 21.23, SD = 3.33; higher scores correspond to healthier family dynamics).

Hypothesis 2. Four meditational models were constructed to determine if caregiver burden mediates the relationship between PD-related impairments and mental health using PROCESS model 4 (Hayes, 2017). Two models were run using motor impairments as a predictor (one for each study site) and another two models were run using non-motor impairments as a predictor (one for each study site). Bootstrapping analysis was used to determine the indirect effect of PD-related impairments on caregiver mental health through caregiver burden. Each model was conducted using 5,000 bootstraps.

Motor Impairments. For the Mexico site, the overall model was significant, $F(2, 145) = 5.54$, $p < .001$, $R^2 = .07$. The direct path from motor symptoms to caregiver burden was statistically significant (b = .32, $p < .001$), as was the path from caregiver burden to caregiver mental health (b = .06, $p = .0016$). The motor impairments model demonstrated a mean bootstrap

estimate of the indirect effect of .02. The obtained confidence interval did not contain 0 (.01, .04), suggesting that caregiver burden mediates the association between motor impairments and caregiver mental health among caregivers from the Mexico site. Overall, this suggests that greater motor impairments predicted greater caregiver burden, which predicted greater mental health deficits among caregivers. The direct effect between motor impairments and mental health was -.01 and was not significant (p = .677), suggesting that caregiver burden fully mediates the association between motor symptoms and caregiver mental health. As noted by Preacher and Hayes (2004), the presence of a direct effect between the predictor and the outcome variable is not necessary to infer the presence of an indirect effect. There may still be a direct effect present, but it is not a condition that must be satisfied to determine that a third variable influences the relationship between a predictor and an outcome.

Similar results were obtained for the United States site. The overall model was significant, $F(2, 102) = 26.48$, $p < .001$, $R^2 = .34$. The direct path from motor symptoms to caregiver burden was statistically significant (b = .44, $p < .001$) as was the path from caregiver burden to caregiver mental health (b = .14, $p < .001$). The motor impairments model demonstrated a mean bootstrap estimate of .06. The obtained confidence interval did not contain 0 (.04, .09), suggesting that caregiver burden mediates the association between motor impairments and caregiver mental health among caregivers from the United States site. Given that the direct effect between motor impairments and mental health was -.03 and was not significant (p = .097), this suggests that caregiver burden fully mediates the association between motor impairments and caregiver mental health.

Non-Motor Impairments. For the Mexico site, the overall model was significant, $F(2, 145) = 6.46$, $p = .002$, $R^2 = .08$. The direct path from non-motor symptoms to caregiver burden

was statistically significant (b = .48, $p < .001$) and the direct path from caregiver burden to caregiver mental health was significant (b = .05, $p = .026$). The non-motor impairments model demonstrated a mean bootstrap estimate of the indirect effect of .02. The obtained confidence interval did not contain 0 (.0036, .04), suggesting that caregiver burden mediates the association between non-motor impairments and caregiver mental health among caregivers from the Mexico site. Similar to the prior model, these results suggest that greater non-motor impairments predict greater caregiver burden, which predicted greater mental health deficits among caregivers. The direct effect between non-motor symptoms and caregiver mental health was .03 and was not significant ($p = .172$), suggesting that caregiver burden fully mediates the association between non-motor impairments and caregiver mental health among caregivers from the Mexico site.

Again, similar results were obtained for the United States site. The overall model was significant, $F(2, 102) = 25.63$, $p < .001$, $R^2 = .33$. The direct path from non-motor symptoms to caregiver burden was significant (b = .65, $p < .001$) and the direct path from caregiver burden to caregiver mental health was significant (b = .14, $p < .001$). The model demonstrated a mean bootstrap estimate of the indirect effect of .09. The obtained confidence interval did not contain 0 (.05, .14), suggesting that caregiver burden mediates the association between non-motor impairments and caregiver mental health among caregivers from the United States site. The direct effect between non-motor impairments and mental health was -.03 and was not significant ($p = .203$), suggesting that caregiver burden fully mediates the association between non-motor impairments and caregiver mental health.

Hypotheses 3 and 4. Four conditional process analyses (i.e., moderated mediations) were conducted to determine if family dynamics moderates the associations from the second hypothesis using PROCESS model 59 (Hayes, 2017). Two of these models used motor

symptoms as a predictor (one model for each site) while the other two models used non-motor symptoms as a predictor (one model for each site).

Motor Symptoms. For the Mexico site, the overall model was significant, $F(5, 142) = 6.26$, $p < .001$, $R^2 = .18$. The interaction between motor symptoms and family dynamics in predicting caregiver burden was not significant (b = .01, $p = .348$). The interaction between motor symptoms and family dynamics in predicting mental health was not significant (b = -.00, $p = .919$). The interaction between caregiver burden and family dynamics in predicting mental health was also not significant (b = .00, $p = .337$), which suggests that the direct effects from motor symptoms and caregiver burden to mental health were not moderated by family dynamics. All of the conditional indirect effects of motor symptoms on mental health through caregiver burden at each level of family dynamics were not significant (Table 11). Overall, this suggests that family dynamics do not moderate the mediation outlined in hypothesis 2.

Table 11. *Conditional Indirect Effects of Motor Symptoms on Mental Health Through Caregiver Burden at Levels of Family Dynamics at the Mexico Site (N = 148)*

Family Dynamics	Estimate	95% Bias-Corrected Bootstrap Confidence Interval
Low (50.84)	.0024	(-.0120, .0171)
Moderate (64.00)	.0112	(-.0035, .0278)
High (71.00)	.0175	(-.0059, .0436)

For the United States site, the overall model was significant, $F(5, 99) = 13.68$, $p < .001$, $R^2 = .41$. The interaction between motor symptoms and family dynamics in predicting caregiver burden was not significant (b = .01, $p = .306$). The interaction between motor symptoms and family dynamics in predicting mental health was not significant (b = .00, $p = .696$). The interaction between caregiver burden and family dynamics in predicting mental health was not significant (b = -.00, $p = .140$). All of the conditional indirect effects of motor symptoms on

mental health through caregiver burden at each level of family dynamics were significant, apart from when family dynamics were unhealthier. This just significant indirect effect at unhealthier family dynamics was so close to non-significance that no moderated mediation could be discerned.

Table 12. *Conditional Indirect Effects of Motor Symptoms on Mental Health Through Caregiver Burden at Levels of Family Dynamics at the United States Site (N = 105)*

Family Dynamics	Estimate	95% Bias-Corrected Bootstrap Confidence Interval
Low (52.96)	.0403	(.0000, .0856)
Moderate (64.00)	.0384	(.0166, .0651)
High (72.04)	.0333	(.0042, .0708)

Non-Motor Symptoms. For the Mexico site, the overall model was significant, $F(5, 142) = 6.61$, $p < .001$, $R^2 = .19$. The interaction between non-motor symptoms and family dynamics in predicting caregiver burden was not significant (b = .00, $p = .865$). The interaction between non-motor symptoms and family dynamics in predicting mental health was not significant (b = -.00, $p = .802$). The interaction between caregiver burden and family dynamics in predicting mental health was also not significant (b = .00, $p = .395$), which suggests that the direct effects from non-motor symptoms and caregiver burden to mental health were not moderated by family dynamics. All of the conditional indirect effects of non-motor symptoms on mental health through caregiver burden at each level of family dynamics were not significant (Table 13). Overall, these results suggest that family dynamics do not moderate the meditational model in hypothesis 2.

Table 13. *Conditional Indirect Effects of Non-Motor Symptoms on Mental Health Through Caregiver Burden at Levels of Family Dynamics at the Mexico Site (N = 148)*

Family Dynamics	Estimate	95% Bias-Corrected Bootstrap

		Confidence Interval
Low (50.84)	-.0004	(-.0301, .0239)
Moderate (64.00)	.0091	(-.0115, .0324)
High (71.00)	.0145	(-.0152, .0516)

For the United States site, the overall model was significant, $F(5, 99) = 14.06$, $p < .001$, $R^2 = .42$. The interaction between non-motor symptoms and family dynamics in predicting caregiver burden was not significant (b = .01, $p = .269$). The interaction between non-motor symptoms and family dynamics in predicting mental health was not significant (b = .00, $p = .300$). The interaction between caregiver burden and family dynamics in predicting mental health was also not significant (b = -.00, $p = .059$). All of the conditional indirect effects of non-motor symptoms on mental health through caregiver burden at each level of family dynamics were significant (Table 14). Again, these results suggest that family dynamics do not moderate the meditational model in hypothesis 2.

Table 14. *Conditional Indirect Effects of Non-Motor Symptoms on Mental Health Through Caregiver Burden at Levels of Family Dynamics at the United States Site (N = 105)*

Family Dynamics	Estimate	95% Bias-Corrected Bootstrap Confidence Interval
Low (52.96)	.0650	(.0149, .1365)
Moderate (64.00)	.0559	(.0229, .0960)
High (72.04)	.0429	(.0026, .0887)

Exploratory Analyses

A frequency distribution was created to examine the frequency of suicidal and self-injurious thoughts among caregivers between sites (Table 15).

Table 15. *Frequency of Suicidal and Self-Injurious Thoughts Over Past Two Weeks (N = 253)*

Variable	Value	
	United States	Mexico
Not at all (%)	97.1%	89.2%
Several days (%)	2.9%	9.5%
More than half the days (%)	0.0%	0.7%
Nearly every day (%)	0.0%	0.7%

There were significant differences on suicidal and self-injurious thoughts between sites, $t(251) = -2.36$, $p = .019$, such that caregivers from the Mexico site ($M = .13$, $SD = .41$) had more frequent suicidal and self-injurious thoughts than the United States site ($M = .03$, $SD = .17$).

There was a similar gender distribution among caregivers between sites, $\chi^2 = 1.892$ (1), $p = .169$ with 68.6% of caregivers self-identifying as women from the United States site and 76.4% of caregivers self-identifying as women from the Mexico site.

An ANCOVA was conducted to determine whether site differences in caregiver burden were present when controlling for caregiver age. The covariate, caregiver age, was not significantly related to caregiver burden, $F(1, 253) = .009$, $p = .925$. A significant effect of site after controlling for caregiver age was still present, $F(1, 253) = 21.07$, $p < .001$, partial $\eta^2 = .078$. Planned simple contrasts of estimated marginal means after controlling for age demonstrated that caregivers from the United States site, 95% CI [12.82, 16.30], reported higher caregiver burden than those from the Mexico site, 95% CI [7.53, 10.38], suggesting that this site difference was not due to age.

Discussion

The current study examined caregivers of individuals with PD in Henrico, Virginia, and Guadalajara, Mexico and the relations among PD-related impairments, caregiver burden,

caregiver mental health, and family dynamics. Pearlin's (1990) conceptual framework of caregiver stress was used to examine caregiver burden (caregiver outcome) as a mediator in the relation between PD-related impairments (primary stressor) and caregiver mental health (caregiver outcome) as well as family dynamics (secondary stressor) as a moderator of this relationship. In addition, differences in caregiver burden and mental health (both caregiver outcomes) and family dynamics (secondary stressor) were explored between the two sites. Overall, results of the current study support Pearlin's (1990) conceptual model as well as suggest targets for intervention and future research opportunities. This discussion will summarize the findings from the current study, compare and contrast the current findings with prior literature, outline clinical implications for caregivers of individuals with PD, as well as future directions and limitations of the current study.

Sample Demographics

Caregivers between the two study sites differed on a number of demographic characteristics, including age, hours per week providing care, and employment status. Specifically, caregivers at the United States site were older than those at the Mexico site. This may be partially explained by relationship status to the individual they provide care for. For example, at the United States site, 93.3% of caregivers were spouses, while only 51.4% were spouses at the Mexico site. However, 34.5% of caregivers at the Mexico site were children of the individual they provide care for, suggesting they would be younger in age. This may in part be explained by cultural values and norms in Mexico. For example, individuals may be more likely to live in multigenerational homes, which may promote caregiving of parents. In addition, familismo and marianismo may promote caregiving among women in Latin America.

Caregivers from the Mexico site reported spending significantly more hours providing care each week than those from the United States site. Given there were no significant differences between sites on either motor or non-motor impairments, the difference in hours providing care may not be due to symptom severity. Time spent caring in the current sample of caregivers is also higher than other samples of caregivers of individuals with neurological conditions in Mexico. For example, a sample of caregivers of individuals with multiple sclerosis in Guadalajara, Mexico reported on average spending 70.96 hours a week providing care (Mickens et al., 2018), nearly 40 hours less than caregivers from the current sample. A more thorough investigation of caregiving activities among PD caregivers in Mexico may serve to explain the number of hours spent caregiving.

There were also differences in employment, such that the most common employment status among caregivers from the United States was retired (64.8%) while only 6.1% of caregivers from the Mexico site reported being retired. This may be in part due to the age differences between the samples, as caregivers from the United States were also significantly older. At the Mexico site, the most frequently reported employment status was part-time employment (28.4%) followed by unemployment (22.3%). It is unclear if this is due to economic conditions or not being able to work full-time (or at all) due to caregiving duties. The latter may be a plausible explanation, particularly in light of the substantial amount of time caregivers from the Mexico site reported providing care, which may preclude an individual's ability to maintain employment outside of the home.

Caregivers also reported a number of demographic characteristics on the individual living with PD they care for. Similar to caregiver age, individuals living with PD at the United States were older (M = 71.61, SD = 8.13) than those at the Mexico site (M = 65.68, SD = 10.78). There

was also a significant relation between gender and site, with more females living with PD at the Mexico site (48.0%) compared to the United States site (35.2%). This is particularly interesting given that the majority of individuals living with PD are men (Van Den Eeden et al., 2003). Given that there have been such few studies on PD epidemiology in Latin America, it is difficult to determine if there is a higher prevalence rate among women in Mexico or Latin America compared to other geographic regions. Further, as the majority of caregivers from the Mexico site self-identified as women, this may also suggest that there are women family members caring for women living with PD, particularly daughters or sisters. This may in part be due to cultural values such as familismo and marianismo that encourage women to engage in caregiving activities for family members.

Hypothesis 1: Differences in Caregiver Burden, Mental Health, and Family Dynamics Between Sites

The first hypothesis predicted that there would be significant mean differences in caregiver burden and mental health between the United States and Mexico sites due to differences in resources (e.g., health care, pharmacological interventions) as well as cultural values (e.g., familismo) between study sites. This hypothesis was partially supported. Although caregivers at the United States experienced greater burden, there were no significant differences in mental health between the United States and the Mexico site.

There are several potential reasons why caregivers in the United States sample reported greater levels of burden. It is possible that caregivers in Mexico experienced lower burden as a result of providing care in the context of cultural factors, such as familismo and respeto. These two cultural values encourage the importance of caring for the family as well as respecting elders (Neary & Mahoney, 2005), which may promote caregiving and even make it a point of cultural

pride. As such, individuals at the Mexico site may view the opportunity to care for their loved one as meaningful and gratifying instead of burdensome.

A number of demographic differences, such as relationship to the individual living with PD and time spent caregiving between sites, may also support the role of cultural values in the differences in caregiver burden. For example, 34.5% of caregivers at the Mexico site were children of individuals living with PD compared to 3.8% of caregivers at the United States site, which may be in part due to cultural differences that encourage looking after older family members. At least one study has found that burden is greater among spousal caregivers (Viwattanakulvanid et al., 2014), which may also partially explain the differences in caregiver burden as over 90% of caregivers at the United States site were spouses while only 51.4% of caregivers at the Mexico site were spouses.

The majority of studies on PD caregivers have found no (Martinez-Martin et al., 2008; Martínez-Martín et al., 2007; Shin, Lee, Youn, Kim, & Cho, 2012) or only weak associations (Kim et al., 2007; Razali, Ahmad, Rahman, Midin, & Sidi, 2011; Tew, Naismith, Pereira, & Lewis, 2013) between the amount of hours spent providing care and caregiver burden. Although the bivariate correlation at the United States site between personal strain and hours per week providing care was significant ($r = .359$, $p < .001$), it was not significant at the Mexico site ($r = .152$, $p > .05$). However, caregivers at the Mexico site spent significantly more time (107.39 hours vs. 60.43 hours) providing care than those at the United States site, yet caregivers from the United States site still reported significantly more caregiver burden.

In the Mexico sample, personal strain and role strain were not associated with any caregiver or patient demographic variables, including caregiver age and education, patient age,

how many individuals assist with providing care, care provided (hours per week and months providing care) or time since diagnosis.

As noted previously, greater PD symptom severity has been associated with greater levels of caregiver burden (Mosley et al., 2017). Given that there were no significant differences between sites in either motor or non-motor symptoms, the higher levels of burden reported by caregivers at the United States site cannot be explained due to motor or non-motor symptom severity. Similarly, there were no differences in the number of individuals who assist the caregiver in providing care across sites. Therefore, the disparity in levels of burden is also not explained by having these additional resources. Taken together, these results may further suggest that cultural values are at least in part responsible for the lower levels of burden among caregivers from the Mexico site.

In addition, Latino caregivers are less likely to institutionalize the individual they provide care for (Dilworth-Anderson et al., 2002) and are less likely to use formal support services (Dilworth-Anderson et al., 2002; Pinquart & Sörensen, 2005), both of which may be associated with caregiver burden. Therefore, overall, the results of the current study suggest that despite the potential for reduced access to resources as well as additional challenges, this does not translate to higher levels of caregiver burden among caregivers from the Mexico site.

The majority of caregivers at both the United States site (67.62%) and the Mexico site (62.85%) reported minimal depression. Almost a quarter of caregivers at the United States site reported mild depression (22.86%) while 25.0% of caregivers at the Mexico site reported mild depression. Very few caregivers at either site reported moderate (6.66% United States, 8.78% Mexico), moderate-severe (1.90% United States, 2.03% Mexico), or severe depression (.95% United States, 1.35% Mexico). Overall, this suggests that the sample was generally not

depressed, although a small portion of caregivers from each site experienced moderate or high levels of depression.

Similarly, the majority of caregivers reported minimal anxiety at both the United States site (61.90%) and the Mexico site (65.54%). Caregivers reported moderate (4.76% United States, 6.76% Mexico) and severe anxiety (5.71% United States, 4.73% Mexico) more frequently than they reported moderate and severe depression, which is in line with prior research that has demonstrated that anxiety is more common among PD caregivers than depression (Martinez-Martin et al.,2008). However, overall, caregivers at both sites were generally not experiencing severe anxiety symptomatology.

Interestingly, there were no significant differences in anxiety and depression despite higher levels of reported burden among caregivers at the United States site. Although the current study hypothesized that greater burden would lead to greater mental health issues, the higher levels of burden among caregivers at the United States site did not correspond to higher levels of anxiety or depression. Overall, these results may suggest that caregiver burden may be a more critical intervention target than depression and anxiety among PD caregivers from the United States.

In addition, it is possible that cultural norms and values may have influenced the responses of PD caregivers at the Mexico site. For example, mental illness in Latin America is often conceptualized as *nervios,* an innocuous term used to describe situational stress and used to avoid the perception of serious mental illness, *locura* (Applewhite, Biggs, & Herrera, 2009; Guarnaccia, Martinez, & Acosta, 2005). Given the stigma associated with mental illness, individuals may experience shame associated with their symptoms (Acuña & Bolis, 2005). This may be particularly important, as caregiver responses from the Mexico site were collected orally

from clinic study staff. As such, caregivers may have been more reluctant to provide this information orally than if they had completed the survey confidentially, and the stigma of mental health issues in Mexico may have influenced responding.

Finally, differences in family dynamics between the two sites were also explored. Although there were no statistically significant differences on the struggling to adapt or overwhelmed by difficulties subscales (all p's < .05) between sites, caregivers at the Mexico site (M = 20.06, SD = 3.81) reported more disrupted communication than those at the United States site (M = 21.23, SD = 3.33; higher scores correspond to healthier dynamics; note that the Disrupted Communication subscale was reverse-scored to match the valence of the other subscales, such that lower scores on this subscale reflect worse communication). This is a particularly interesting finding in light of the cultural values of familismo and respeto in Latin America, which in theory promote family relationships. However, it is possible that due to these cultural values, caregivers may experience difficulties in expressing their subjective experiences and feelings regarding caregiving, which may lead to subjective feelings of poor communication among family members. Given that there is no research on communication among families with individuals with PD in Latin America, this may be an important target for future research.

To date, this is the first study to make a cross-cultural comparison between caregivers from the United States and Latin America on PD-related impairments, caregiver burden and mental health, and family dynamics. As very little research has been published on caregivers of individuals with PD in Latin America, it is difficult to discern how the results of the current study may generalize to the overall population of PD caregivers in Latin America, but the current findings provide a starting point for building a more substantial body of PD caregiving research in the region.

Hypothesis 2: Caregiver Burden as a Mediator of the Association between PD-Related Impairments and Caregiver Mental Health

The second hypothesis predicted that caregiver burden would mediate the association between PD-related impairments and caregiver mental health. One model specified motor impairments as a predictor while the other model specified non-motor impairments as a predictor, with each of these models run separately for each site. Results from both the motor and non-motor impairments models suggest that caregiver burden fully mediates the association between PD-related impairments and caregiver mental health in both caregivers from the United States and from Mexico.

Generally, prior research has supported the links between PD-related impairments and caregiver burden (Mosley et al., 2017), caregiver burden and mental health (Grun et al., 2016), and PD-related impairments and mental health (Fernandez et al., 2001; Martinez-Martin et al., 2008). To date, this is the first evidence that caregiver burden fully mediates the relations between PD-related impairments and mental health. One possible explanation for these results is that as PD-related impairments become more severe, levels of caregiver burden increase, which in turn may lead to poorer mental health.

Interestingly, for both study sites, there was no direct effect from motor symptoms to caregiver mental health. Although prior research has suggested that non-motor symptoms explain more variance than motor symptoms in caregiver outcomes such as caregiver strain (Carter et al., 2008), research has generally found that indicators of motor symptoms such as PD severity and length of disease are associated with caregiver mental health (Fernandez et al., 2001; Martinez-Marti et al., 2008). However, in the current study, motor symptoms were not even correlated with either depression or anxiety at either study site.

This may be in part be due to the generally normal to moderate motor symptoms reported by the caregiver in the current study. Across both sites, less than 10% of individuals with PD were categorized as "severe" on any motor symptom by their caregiver, apart from 12.2% of caregivers from the Mexico sample who reported the individual they care for is severely restricted doing hobbies and other activities. Prior research has also found that PD duration significantly predicts caregiver depression, such that caregivers who care for an individual who has a longer time since diagnosis self-report higher levels of depression (Fernandez et al., 2001).

Further, individuals living with PD are often institutionalized during the final stages of the disease when symptoms are most significant. Given that both samples were recruited from outpatient clinics and the level of symptoms reported by caregivers, it is likely that the motor symptoms in the current study may not yet be severe enough to influence caregiver mental health. Future research should classify individuals by disease stage to determine how this may or may not influence caregiver mental health.

Prior researchers have posited that non-motor symptoms may be particularly difficult for caregivers to cope with as they may change the emotional aspect of the relationship between the patient and the caregiver (Mosley et al., 2017). However, relatively few studies have examined PD-related impairments and caregiver mental health. As such, future research should continue to explore this area.

Hypothesis 3: Family Dynamics as a Moderator in the Mediational Models

The third hypothesis posited that family dynamics would moderate the mediation models listed in hypothesis 2. Four separate models were run in order to determine if family dynamics moderated the associations from the second hypothesis. Two of these models used motor symptoms as a predictor (one model for each site) while two models used non-motor symptoms

as a predictor (one for each site). For all four models, family dynamics did not moderate the meditational models.

The general lack of research on family dynamics in PD caregiving precludes in-depth comparisons between the current study and other research. Although this was the first study to examine family dynamics as a potential moderator in the relations between PD-related impairments, caregiver burden, and caregiver mental health, no studies have examined family dynamics as a mediator. It is possible that family dynamics may act as a predictor or mediator instead of a moderator. For example, a recent study among 95 caregivers of individuals living with PD from Mexico found that caregiver burden fully mediates the relation between family cohesion and caregiver mental health-related quality of life (Trapp, Ertl, Gonzalez-Arredondo, Rodriguez-Agudelo, & Arango-Lasprilla, 2018). The researchers posited that families with greater family cohesion may have stronger emotional bonds and can better cope and adapt to stressors, which may reduce caregiver distress (Trapp et al., 2018) and may support family dynamics as a predictor of caregiver mental health. Therefore, there is at least some evidence suggesting that family processes influence critical outcomes such as caregiver burden and caregiver mental health in Latin America and may act as an important predictor variable.

To date, the majority of studies on PD caregiving primarily focus on spousal caregivers, leaving a gap in the literature regarding the experiences of other caregivers, such as children. This may be critical for Latin American populations given the cultural values of familismo, where children may be encouraged to participate in caregiving activities for their elders. Indeed, in the current study, far more caregivers from the Mexico site were children as opposed to spouses, which may have influenced response patterns on the family dynamics measure utilized in the current study. To date, very few studies have incorporated the experiences of children or

adult children caregivers of individuals living with PD. One such study by Schrag, Morley, Quinn, and Jahanshahi (2004) in England found that younger children perceived higher burden and greater impact on their social lives than older children. However, older children reported more impairment of family functioning than younger children.

One recent study on the needs of family caregivers and non-primary caregivers of individuals with PD found that non-primary caregivers were especially interested in information modules on sharing their experiences with other relatives (Sturm, Folkerts, & Kalbe, 2019), suggesting that family communication strategies are of interest to at least some caregivers of individuals with PD. Therefore, future research may seek to create information modules or interventions that focus on delivering assistance with sharing caregiving experiences with other relatives.

Although there are very few studies that examine family functioning or relationship quality among PD caregivers, the existing literature suggests that diminished support for the caregiver and family relationship quality influence important outcomes such as institutionalization of the individual with PD (Kao & Stuifbergen, 1999). Further, there is support in the literature on the importance of family functioning among other clinical groups in Latin America, such as traumatic brain injury (Perrin et al., 2013) and individuals living with dementia (Sutter et al., 2014), suggesting the PD caregiving literature would benefit from additional studies in this area.

Hypothesis 4: Family Dynamics Will be a Stronger Buffer for the Mexico Site Compared to the United States Site

The fourth hypothesis posited that family dynamics would be a stronger buffer (i.e., explain more variance) for caregivers at the Mexico site compared to caregivers at the United

States site due to cultural values that may influence the caregiving process. This hypothesis was not supported. Instead, family dynamics explained more variance in caregivers from the United States sample compared to the Mexico sample by a wide margin in both the models that used motor symptoms and the models that used non-motor symptoms as predictors.

In the models using motor symptoms as a predictor, the model explained 41% of the variance at the United States site (R^2 = .41) variance at the United States site compared to the Mexico site, where the model only explained 18% of the variance (R^2 = .18). In the models using non-motor symptoms as a predictor, the model explained 42% of the variance at the United States site (R^2 = .42) compared to only 19% (R^2 = .19) at the Mexico site.

Similarly, in the mediational models in hypothesis 2, more variance was explained at the United States site when compared to the Mexico site, both for the models using motor and non-motor symptoms as predictors. Therefore, it is not solely the addition of family dynamics as a moderator that was responsible for the disparities in variance explained in the models for hypothesis 4. Instead, this may suggest that the disparities are possibly related to the sample or the measures used.

For example, although the study measures had all been translated and validated (apart from the family dynamics measure), it is possible that these measures are not as culturally relevant for caregivers outside of the North American and European cultural context. Further, it is possible that variables apart from those captured in the current study would better predict outcomes for caregivers in the Mexico sample. For example, incorporating more direct measures of the importance of the family and/or caring for family members and elders may be more relevant to this population. In addition, it may be helpful to capture more information regarding the family structure of the caregivers. As mentioned previously, cultural values such as

familismo may promote multigenerational homes as well as taking care of elders. As such, it is possible that caregivers in the current study from the Mexico sample were reporting dynamics of much larger and/or closer family systems than caregivers from the United States. Future research on family structure may serve to further clarify how family dynamics may or not may not influence critical caregiver outcomes such as caregiver burden and mental health.

Exploratory Analyses

Suicidal and self-injurious thoughts. Although overall very few caregivers between study sites endorsed suicidal or self-injurious thoughts, an exploratory analysis demonstrated that caregivers from the Mexico site more frequently endorsed suicidal or self-injurious thoughts. This was particularly interesting given that caregivers from the United States reported higher levels of caregiver burden and that there were no significant differences in either depression or anxiety between sites. Further, mental health can be seen as taboo in Latin America (Acuña & Bolis, 2005), and suicide is against the teachings of Catholicism, a major cultural influence in the region. Catholicism has even been found to be a protective factor against suicide among Latino individuals born outside of the United States (Barranco, 2016).

Although caregivers have been shown to have worse mental health than the general population (Cooper, Balamurali, & Livingston, 2007; Joling et al., 2010), there is relatively little research on suicidality and completed suicide among caregivers. A review of the literature did not find any studies on suicidality among PD caregivers; however, census-based studies and studies examining caregivers of individuals with other neurological diseases (e.g., dementia) have been conducted. One longitudinal epidemiological study of English caregivers found no increased risk of suicide risk among caregivers compared to non-caregivers (O'Reilly, Rosato, Maguire, & Wright, 2015). Interestingly, there were no differences in suicide risk between

caregivers and non-caregivers that reported poor mental health at baseline. Further, caregivers who did not report poor mental health at baseline had lower suicide risk than their non-caregiving counterparts.

A study by O'Dwyer, Moyle, Zimmer-Gembeck, and Leo (2016) on caregivers of individuals with dementia found that 16% of caregivers had contemplated suicide in the past year. Depression significantly predicted suicidal ideation among caregivers while age and reasons for living were demonstrated to be protective factors. Further, satisfaction with social support had an indirect effect on suicidal ideation through depression.

Another study of caregivers of individuals with dementia found that 4.7% of the sample reported suicidal thoughts (Joling, O'Dwyer, Hertogh, & Hout, 2018). Compared to caregivers without suicidal thoughts, those who reported suicidal thoughts had more severe anxious and depressive symptoms, experienced greater health problems, were lonelier, and had a lower sense of competence and mastery. Overall, these studies may suggest that social support and mental health issues may be key risk factors for suicidal ideation among caregivers and may be an important clinical topic.

The findings on the relations between social support and suicidal ideation may be particularly important for caregivers from the Mexico site due to values such as familismo which promote family relationships as well as marianismo which encourage women (who are more likely to assume the caregiver role) to take care of their families. Theoretically, it would be assumed that these factors might be associated with reduced suicidal ideation, although that was not found in the current study. Future research should be conducted to determine risk factors for suicide ideation among caregivers from Latin America as well as develop culturally tailored interventions for caregivers.

The PHQ-9 was used to assess suicidal and self-injurious thoughts at both sites. Although the PHQ-9 has been translated into Spanish in prior research (Diez-Quevedo et al., 2001; Donlan & Lee, 2010; Wulsin et al., 2002) and has been used in other studies of caregivers of individuals with neurological disorders such as dementia in Latin America (Sutter et al., 2014), it is unclear if this measure is culturally relevant. One study of individuals in a rural, highly marginalized primary care center in rural Mexico found that 26% of participants reported suicidal or self-injurious thoughts with 9% reporting these more than half the days in the previous two weeks (Arrieta et al., 2017) , which is higher than the rates reported in the current study. In the Arrieta sample, only .5% of participants reported that they did not understand the item, suggesting that the vast majority of the sample understood what the item was assessing. Similar to the methodology in the current study, participants completed the measure orally due to concerns surrounding low levels of literacy, as such; an interviewer was able to ensure participants understood the item. Therefore, although evidence supporting how well this item translates cross-culturally is weak, there is at least some evidence suggesting that participants understand what the item is asking.

Gender differences in caregiving between sites. There were no gender differences in caregivers between sites. However, these results should be interpreted with caution as it is possible that the demographics of caregivers in the current study may not be similar to PD caregivers overall. For example, the caregivers from the United States site were sampled from a PD specialty clinic that has a generally equal distribution of male and female caregivers. As PD is more common among men (Van Den Eeden et al., 2003) and caregivers of individuals living with PD are often spouses, it would be reasonable to expect that there are more women caregivers than male caregivers.

There was more diversity among caregivers from the Mexico site, such that 34.5% identified as children and 7.5% identified as siblings of the individual living with PD. As 76.4% of caregivers from the Mexico site identified as female, this may suggest that there may be more daughters, sisters, and other female caregivers in this cultural context compared to the United States. This makes sense in light of cultural values such as familismo and marianismo that encourage women to take on the role of caregiver for family members.

Caregiver Burden and Age. Caregivers from the United States were significantly older and reported more burden than caregivers from the Mexico site. An ANCOVA demonstrated that levels of caregiver burden between the United States and Mexico were still significantly different even when controlling for caregiver age.

One systematic review of PD caregivers found that caregiver age is generally not associated with caregiver burden (Greenwell, Gray, Wersch, Schaik, & Walker, 2015). However, the majority of the studies included in the systematic review were based in North America or Europe and may not be applicable to the Latin American cultural context. To date, the only cross-cultural study on PD caregiver strain between caregivers from the United States and Japan did not find significant differences in burden despite demographic differences between the samples (Tanji et al., 2013). As such, it is possible that the cultural context of Latin America may influence caregiver experiences and may partially explain why differences in burden exist.

Implications for Pearlin's Caregiving Stress Process Model (1990). Results of the study also largely supported the Pearlin et al. (1990) caregiving stress process model. PD-related impairments (a primary stressor) predicted caregiver burden (caregiver outcome) in the mediational model across both sites, which supports the Pearlin model. However, PD-related impairments did not predict caregiver mental health (caregiver outcome) at either site, which did

not support Pearlin's theoretical framework. Caregiver burden also significantly predicted caregiver mental health across both sites; however, this relationship is not specified within Pearlin's original caregiving stress process model. As such, the current study also lends support to the relations between caregiver outcomes such as burden and mental health.

Family dynamics (secondary stressor) was not found to be a moderator of the mediational model in hypothesis 2. However, Pearlin's model suggests that secondary stressors such as family dynamics are associated with caregiver outcomes such as burden and mental health, which was supported in the bivariate correlations across both sites.

Finally, as this model was originally developed for caregivers of individuals with dementia, it is possible that there are unique aspects to the PD caregiving experience that do not mirror the experiences of caregivers of other neurological conditions (i.e., relation between impairments and caregiver mental health). As such, future research in this area is warranted.

Clinical Implications

The current study suggests a number of intervention targets for caregivers of individuals living with PD in both the United States and Mexico, particularly caregiver burden, caregiver mental health, and family dynamics. Given the evidence suggesting that patient characteristics affect caregivers (Mosley et al., 2017), interventions addressing the individual living with PD as well as the broader family system may also serve to improve caregiver psychosocial functioning and well-being.

PD-Related Impairments. PD-related impairments, particularly non-motor symptoms, were associated with deleterious outcomes for caregivers in the current study, such as caregiver burden. Given that symptom severity is also associated with outcomes such as burden, it may be important for health care providers of caregivers to be mindful of PD-related impairments and

how they may affect the psychosocial functioning and well-being of the caregiver. Interventions that target PD-related impairments may also be useful in reducing caregiver burden and have already received some support in the literature.

For example, interventions that promote independence and functioning among individuals with PD may be associated with reduced caregiver burden. Recently, exercise interventions for individuals with PD have received attention. Oguh, Einstein, Kwasny, and Simmuni (2014) conducted a study of individuals with PD at baseline and at a one-year follow up. Their findings indicated that individuals with PD who exercised more than 150 minutes a week had better quality of life, physical function, reduced disease progression, as well as less caregiver burden among their caregivers than those who were not regular exercisers.

Targeting non-motor symptoms may also serve to reduce deleterious outcomes for caregivers, such as caregiver burden. For example, previous studies have shown that addressing dementia with cognitive enhancers has been associated with reduced caregiver burden (Litvinenko, Odinak, Mogil'naya, & Emelin, 2008; Reading, Luce, & McKeith, 2001). Prior research has also demonstrated that tailored cognitive behavioral therapy for individuals with PD with anxiety is associated with reduced caregiver burden post-intervention (Dissanayaka et al., 2017). Overall, these studies suggest that there is benefit in considering PD-related impairments for caregivers, particularly as it may relate to caregiver burden.

It is important to note that these studies were not conducted in Latin America or with diverse samples. As such, future research should seek to determine if these interventions are also effective among individuals with PD in other geographic regions and among racially and ethnically diverse samples.

Caregiver burden. The current study suggests that reducing caregiver burden is an important target for intervention. To date, there have been a number of interventions that target burden among caregivers of individuals with PD. One educational intervention that addressed the scheduling of pleasant activities, communication, reducing burden, and managing stress was shown to significantly reduce burden from baseline (Simons, Thompson, & Smith-Pasqualini, 2006). Further, interventions emphasizing education and fellowship with fellow caregivers have also been reported in the literature and have received qualitative support for reducing caregiver burden (McLaughlin et al., 2011; Roland, Jenkins, & Johnson, 2010; Schrag et al., 2004).

However, again, none of these interventions were conducted in Latin America and did not consist of diverse samples (in terms of race/ethnicity, languages spoken, etc.). Therefore, it is unclear if these interventions would be effective in this geographical region. As such, another critical target for intervention is the development and evaluation of interventions that may be culturally adapted for caregivers living in Latin America.

Caregiver mental health. In the current study, 22.86% of caregivers from the United States site and 25.0% of caregivers from the Mexico site reported at least mild depression. Similarly, 27.62% of caregivers from the United States and 22.97% reported at least mild anxiety. Given the demonstrated associations between mental health and deleterious outcomes for caregivers (e.g., burden), caregiver mental health may be an important intervention for caregivers. To date, at least one cognitive behavioral intervention has been shown to reduce caregiver burden among caregivers who report emotional distress. Secker and Brown (2005) found that 12 to 14 sessions of cognitive behavioral therapy focused on relaxation, sleep hygiene, accessing support, and challenging negative beliefs delivered by a clinical psychologist reduced burden six months post-intervention compared to the control group.

Given the lack of mental health interventions for caregivers of individuals with PD in Latin America, interventions that are culturally tailored for this population may serve to address the mental health needs of PD caregivers in a culturally sensitive manner.

Family dynamics. Caregivers at the Mexico site reported significantly higher levels of disrupted communication than caregivers at the United States site, which may suggest that improving communication processes within families may be an important target for intervention among these caregivers. To date, there have been no interventions for individuals with PD and their families that focus on communication strategies. This may be particularly important for individuals from Latin America where cultural values promote caregiving for family members.

Given prior research that shows family cohesion is linked to caregiver outcomes such as caregiver burden and reduced mental health-related quality of life (Trapp et al., 2018), as well as results from the current study that demonstrate poor family dynamics are associated with caregiver burden and reduced mental health, interventions that incorporate the entire family system as opposed to just the primary caregiver may be particularly useful for caregivers of individuals living with PD.

Limitations and Future Research

Methodological weaknesses in data collection. The present study is limited in that it only recruited from two outpatient clinics: a specialty neuropsychology clinic in Henrico, Virginia, and a neuropsychology clinic in Guadalajara, Mexico. As such, the current study likely did not capture caregivers of individuals in the later stages of PD, where individuals are likely to be institutionalized (Deloitte Access Economics, 2015). Given evidence demonstrating caregiver burden is highest in stage IV immediately prior to institutionalization at stage V (Deloitte Access

Economics, 2015), the relationships identified in the current study among outpatient caregivers may not generalize to all PD caregivers.

The data in the current study were collected using slightly different methodology at the Mexico site and the United States site. At the United States site, caregivers completed the study measures independently using paper and pencil. In contrast, at the Mexico site, researchers used oral interviews to collect data from participants (in order to account for potential problems with illiteracy), which may have influenced the responses of participants. In addition, the study measures utilized in the current study (apart from the MDS-UPDRS) were validated for self-report and not for oral interviews. Therefore, it is possible that caregivers from the Mexico site responded differently from caregivers from the United States site.

Another limitation is that the data in this study were collected exclusively from caregivers. Therefore, the data in the current study represent their perceptions of PD-related impairments, caregiver burden and mental health, and family dynamics. Future studies should aim to also use more objective measures such as patient medical records to assess PD-related impairments. It may be particularly helpful to collect objective information on disease stage, which has been directly associated with deleterious outcomes for caregivers such as burden (Martínez-Martín et al., 2007).

Information on any past or current PD treatment interventions was also not collected. Although it is likely that the majority of caregivers in the current study at the United States site were caring for an individual receiving pharmacological treatment, there is very little information on how many individuals living with PD receive the standard pharmacological treatments in Latin America or what alternative treatment approaches may be used. Prior research found that pharmacological treatment is not as easily accessible in Latin America

(Troiano, Micheli, Alarcón, & Teive, 2006), which may suggest that their use was not as frequent as at the United States site. In one sample of PD patients from a tertiary referral center, Rodríguez-Violante, Cervantes-Arriaga, Villar-Velarde, and Corona (2010) reported that 40% of patients were on levodopa alone, 20% received a dopaminergic agonist alone, and 36% were on a combination of levodopa and a dopaminergic agonist. However, in the absence of additional data, it is unclear how this sample may generalize to the overall population, particularly populations without access to care.

Troiano et al. (2006) noted that the high cost of pharmacological treatment for PD is a pervasive problem in Latin America. One study of Chilean individuals living with PD found a relation between income, dose and cost of pharmacological treatments, and frequency of physician visits (Chaná & Galdames, 1998). Further, due to the high cost of pharmacological treatments, many individuals living with PD delay treatment until they experience significant disruption in their activities of daily living or disability (Cardoso, Camargos, & Silva Júnior, 1998). Interestingly, despite the possible differences in pharmacological treatment use between sites, there were no statistically significant differences in either motor or non-motor symptoms. Patient medical records and treatment information may serve to clarify why there were no caregiver reported differences in PD-related impairments between sites. Future research should incorporate information on what treatments, if any, individuals are receiving (e.g., psychological, pharmacological, exercise interventions, etc.).

Further, there were significant differences between sites on key variables such as hours providing care and relationship to the individual living with PD that could not be controlled for in the analyses in the current study. Given the differences in everyday life for individuals between Mexico and the United States, it is difficult to pinpoint explanations as to why.

Although there were statistically significant differences in hours providing care, the current study did not capture specific caregiving tasks that participants engaged in that they perceive as caregiving. However, given the disparities in resources (e.g., technology, assistive devices) between the two countries, it is possible that caregivers from Mexico had to spend considerably more time on tasks such as food preparation and activities of daily living.

The current study also did not examine how the models examined may differ by relationship to the patient. For example, spousal caregivers may have already spent a substantial amount of time with their spouse through living a common life together and may not perceive some tasks or activities of daily living as a substantial deviation from their typical relationship. In contrast, non-spousal caregivers such as adult children, siblings, etc.

Cross-sectional methodology. Given that the current study was cross-sectional in nature, causal inferences cannot be made. As such, future research should utilize cross-lagged panel designs or other longitudinal methods to infer whether the relations identified in the current study may be causal in nature. Further, it is possible that some of the relations are reciprocal. For example, it is also possible that mental health deficits also influence levels of caregiver burden.

Cultural relevance of study measures. Although each measure included in the current study had been previously translated into Spanish, and all were validated in Spanish apart from the SCORE-15, it is possible that the measures, originally developed in North America, may not best represent the manifestations of these constructs in different cultural contexts, such as Latin America.

There is strong support for the use of the Spanish versions of the PHQ-9, ZBI Short Form, and GAD-7 (Huang, Chung, Kroenke, Delucchi, & Spitzer, 2006; Martín-Carrasco et al., 2016; Mills et al., 2014; Wulsin et al., 2002), suggesting that these measures may be appropriate

for use in Spanish speaking populations and may not be vulnerable to invariance due to cultural differences. However, these measures have not been used extensively among Spanish-speaking caregivers, particularly those of caregivers of individuals living with PD.

In addition, although the MDS-UPDRS has been validated in Spanish (Goetz et al., 2008; Martinez-Martin et al., 2013), there is no normative data on PD symptomatology in Mexico or Latin America. As such, it is unclear how the caregiver-reported PD-related impairments from the current sample may generalize to individuals living with PD across Latin America, particularly those without access to adequate medical care.

Finally, the SCORE-15 has been previously translated into Spanish (Association for Family Therapy & Systematic Practice, n.d.), the measure has not yet been validated in the literature. As such, it is unclear if this measure performs as well as the original version intended for English-speaking individuals. Future research should seek to validate this measure among Spanish-speaking individuals.

To better capture how these constructs manifest in different cultures, using a mixed-methods approach to create culturally relevant measures may be appropriate. To date, there are no PD caregiving measures that were developed for caregivers from Latin America. As previously noted, all of the measures created in the current study were created in the North American or European cultural context. Incorporating the viewpoints of caregivers from Latin America may lead to measures that better capture their experiences and provide a more accurate representation of their caregiving experiences.

Generalizability. Given that the samples in the current study came from two clinics, it is possible that the experiences of these caregivers may not generalize to the population of caregivers of individuals living with PD in the United States and Mexico. For example,

caregivers at the United States site were recruited from a PD specialty clinic in a suburban area, suggesting that the individuals they care for are at least receiving some health care. These caregivers may have important differences from caregivers who do not have access to specialty PD clinics or health care for the individual they provide care for.

Similarly, participants from the Mexico site were recruited from a large, urban hospital, also suggesting they have at least some access to health care. The experiences from caregivers without health care may differ greatly from those who do, such as caregivers in rural areas. Further, there is significant heterogeneity among the Mexican population. Larger urban areas, such as Guadalajara, often consist of populations that are primarily mestizo. Given that the major ethnic groups of Mexico also include indigenous populations and White Mexican individuals, it is possible that these groups may have caregiving experiences that differ from the mestizo population. Further, Latin America is also very culturally heterogeneous. As such, caution should be taken when generalizing the current study to the rest of Latin America.

For example, although Catholicism remains the most popular religion in Mexico, Guadalajara in particular has a high concentration of individuals who self-identify as Catholic compared to other urban centers in Mexico (Gutiérrez Zúñiga & De La Torre Castellanos, 2017). In the city, over half of individuals attend mass weekly and over 40% make votive rituals to virgins and other saints (Gutiérrez Zúñiga & De La Torre Castellanos, 2017). Given prior research that supports the association between organizational religiosity among Hispanic caregivers and positive appraisals or providing care (Epps, 2015), it is possible that caregivers from the Mexico site in the current study experience less burden and better mental health than other caregivers throughout Latin America.

In addition, as both sites recruited from outpatient clinics, it is likely that the individuals cared for do not represent the most severe, late-stages of PD where individuals are likely to be institutionalized (Deloitte Access Economics, 2015). As such, results from the current study may not generalize to caregivers of individuals who reside in institutional settings, such as nursing homes or other long-term care facilities.

Conclusions

The current study examined associations between PD-related impairments, caregiver burden, caregiver mental health, and family dynamics among caregivers of individuals with PD residing in the United States and Mexico. Findings from the current study as well as prior literature highlight the importance of targeting critical caregiver outcomes such as caregiver burden and caregiver mental health. In addition, the current study also suggests that the larger family system is deserving of additional attention in the literature, particularly in Latin America where cultural values promote the importance of the family system. The development of culturally tailored interventions focusing on the caregiver as well as the broader family system may serve to improve the lives of individuals with PD as well as their caregivers.

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Appendices

Appendix A

Movement Disorder Society Unified Parkinson's Disease Rating Scale

The following six questions ask about behaviors that the patient may or may not experience. Some questions concern common problems and some concern uncommon ones. If the patient has a problem in one of the areas, please choose the best response that describes how the patient has felt MOST OF THE TIME during the PAST WEEK.

1. Cognitive Impairment. Over the past week has the patient had problems remembering things, following conversations, paying attention, thinking clearly, or finding your way around the house or in town?
    a. Normal: No cognitive impairment
    b. Slight: Impairment appreciated by patient or caregiver with no concrete interference with the patient's ability to carry out normal activities and social interactions.
    c. Mild: Clinically evident cognitive dysfunction, but only minimal interference with the patient's ability to carry out normal activities and social interactions.
    d. Moderate: Cognitive deficits interfere with but do not preclude the patient's ability to carry out normal activities and social interactions
    e. Severe: Cognitive dysfunction precludes the patient's ability to carry out normal activities and social interactions

2. Hallucinations and Psychosis. Over the past week has the patient seen, heard, smelled, or felt things that were not really there?
    a. Normal: No hallucinations or psychotic behaviour.
    b. Slight: Illusions or non-formed hallucinations, but patient recognizes them without loss of insight.
    c. Mild: Formed hallucinations independent of environmental stimuli. No loss of insight.
    d. Moderate: Formed hallucinations with loss of insight.
    e. Severe: Patient has delusions or paranoia.

3. Depressed Mood. Over the past week has the patient felt low, sad, hopeless or unable to enjoy things? If yes, was this feeling for longer than one day at a time? Did it make it difficult for them to carry out their usual activities or to be with people?
    a. Normal: No depressed mood.
    b. Slight: Episodes of depressed mood that are not sustained for more than one day at a time. No interference with patient's ability to carry out normal activities and social interactions.

   c. Mild: Depressed mood that is sustained over days, but without interference with normal activities and social interactions.
   d. Moderate: Depressed mood that interferes with, but does not preclude, the patient's ability to carry out normal activities and social interactions.
   e. Severe: Depressed mood precludes patient's ability to carry out normal activities and social interactions.

4. Anxious Mood. Over the past week has the patient felt nervous, worried or tense? If yes, was this feeling for longer than one day at a time? Did it make it difficult for them to follow their usual activities or to be with other people?
   a. Normal: No anxious feelings.
   b. Slight: Anxious feelings present but not sustained for more than one day at a time. No interference with patient's ability to carry out normal activities and social interactions.
   c. Mild: Anxious feelings are sustained over more than one day at a time, but without interference with patient's ability to carry out normal activities and social interactions.
   d. Moderate: Anxious feelings interfere with, but do not preclude, the patient's ability to carry out normal activities and social interactions.
   e. Severe: Anxious feelings preclude patient's ability to carry out normal activities and social interactions.

5. Apathy. Over the past week, has the patient felt indifferent to doing activities or being with people?
   a. Normal: No apathy
   b. Slight: Apathy appreciated by patient and/or caregiver, but no interference with daily activities and social interactions.
   c. Mild: Apathy interferes with isolated activities and social interactions.
   d. Moderate: Apathy interferes with most activities and social interactions.
   e. Severe: Passive and withdrawn, complete loss of initiative.

6. Features of dopamine dysregulation syndrome. Over the past week, has the patient had unusually strong urges that are hard to control? Do you feel driven to do or think about something and find it hard to stop?
   a. Normal: No problems present.
   b. Slight: Problems are present but usually do not cause any difficulties for the patient or family/caregiver.
   c. Mild: Problems are present and usually cause a few difficulties in the patient's personal and family life.
   d. Moderate: Problems are presented and usually cause a lot of difficulties in the patient's personal and family life.

e. Severe: Problems are present and preclude the patient's ability to carry out normal activities or social interactions or to maintain previous standards in personal and family life.

Instructions:
This questionnaire will ask you about your experiences of daily living.
There are 20 questions. We are trying to be thorough, and some of these questions may therefore not apply to you now or ever. If the patient does not have the problem, simply mark "a" for NO. Please read each one carefully and read all answers before selecting the one that best applies to you.

We are interested in the average or usual function of the patient over the past week including today. Some patients can do things better at one time of the day than at others. However, only one answer is allowed for each question, so please mark the answer that best describes what you can do most of the time.

The patient may have other medical conditions besides Parkinson's disease. Do not worry about separating Parkinson's disease from other conditions. Just answer the question with your best response.

7. Sleep problems. Over the past week, has the patient had trouble going to sleep at night or staying asleep through the night? Consider how rested they felt after waking up in the morning.
    a. Normal: No problems.
    b. Slight: Sleep problems are present but usually do not cause trouble getting a full night of sleep.
    c. Mild: Sleep problems usually cause some difficulties getting a full night of sleep.
    d. Moderate: Sleep problems cause a lot of difficulties getting a full night of sleep, but they still usually sleep for more than half the night.
    e. Severe: They usually do not sleep for most of the night.

8. Daytime sleepiness. Over the past week, has the patient had trouble staying awake during the daytime?
    a. Normal: No daytime sleepiness.
    b. 1 - Slight: Daytime sleepiness occurs but they can resist and they stay awake.
    c. 2 - Mild: Sometimes they fall asleep when alone and relaxing. For example, while reading or watching TV.
    d. 3 - Moderate: They sometimes fall asleep when they should not. For example, while eating or talking with other people.
    e. 4 - Severe: They often fall asleep when they should not. For example, while eating or talking with other people.

9. Pain and other sensations. Over the past week, has the patient had uncomfortable feelings in their body like pain, aches tingling or cramps?
    a. 0 - Normal: No uncomfortable feelings
    b. 1 - Slight: They have these feelings. However, they can do things and be with other people without difficulty.
    c. 2 - Mild: These feelings cause some problems when they do things or are with other people.
    d. 3 - Moderate: These feelings cause a lot of problems, but they do not stop them from doing things or being with other people.
    e. 4 - Severe: These feelings stop them from doing things or being with other people.

10. Urinary problems. Over the past week, has the patient had trouble with urine control? For example, an urgent need to urinate, a need to urinate too often, or urine accidents?
    a. Normal: No urine control problems
    b. Slight: They need to urinate often or urgently. However, these problems do not cause difficulties with their daily activities.
    c. Mild: Urine problems cause some difficulties with their daily activities. However, they do not have urine accidents.
    d. Moderate: Urine problems cause a lot of difficulties with their daily activities, including urine accidents.
    e. Severe: They cannot control their urine and use a protective garment or have a bladder tube.

11. Constipation problems. Over the past week has the patient had constipation troubles that cause them difficulty moving their bowels?
    a. Normal: No constipation
    b. Slight: They have been constipated. They use extra effort to move their bowels. However, this problem does not disturb their activities or their being comfortable.
    c. Mild: Constipation causes them to have some troubles doing things or being comfortable.
    d. Moderate: Constipation causes them to have a lot of trouble doing things or being comfortable. However, it does not stop them from doing anything.
    e. Severe: They usually need physical help from someone else to empty their bowels.

12. Light headedness on standing. Over the past week, has the patient felt faint, dizzy or foggy when they stand up after sitting or lying down?
    a. Normal: No dizzy or foggy feelings.
    b. Slight: Dizzy or foggy feelings occur. However, they do not cause them trouble doing things.

   c. Mild: Dizzy or foggy feelings cause them to hold on to something, but they do not need to sit or lie back down.
   d. Moderate: Dizzy or foggy feelings cause them to sit or lie down to avoid fainting or falling.
   e. Severe: Dizzy or foggy feelings cause them to fall or faint.

13. Fatigue. Over the past week, has the patient usually felt fatigued? This feeling is not part of being sleepy or sad.
   a. Normal: No fatigue
   b. Slight: Fatigue occurs. However it does not cause them troubles doing things or being with people.
   c. Mild: Fatigue causes them some troubles doing things or being with people.
   d. Moderate: Fatigue causes them a lot of troubles doing things or being with people. However, it does not stop them from doing anything.
   e. Severe: Fatigue stops them from doing things or being with people.

14. Speech. Over the past week, has the patient had problems with their speech?
   a. Normal: Not at all (no problems).
   b. Slight: Their speech is soft, slurred or uneven, but it does not cause others to ask them to repeat themselves.
   c. Mild: Their speech causes people to ask them to occasionally repeat themselves, but not everyday.
   d. Moderate: Their speech is unclear enough that others ask them to repeat themselves every day even though most of their speech is understood.
   e. Severe: Most or all of their speech cannot be understood.

15. Saliva & drooling. Over the past week, has the patient usually had too much saliva during when they are awake or when they sleep?
   a. Normal: Not at all (no problems).
   b. Slight: They have too much saliva, but do not drool.
   c. Mild: They have some drooling during sleep, but none when they are awake.
   d. Moderate: They have some drooling when they are awake but they usually do not need tissues or a handkerchief.
   e. Severe: They have so much drooling that they regularly need to use tissues or a handkerchief to protect their clothes.

16. Chewing and swallowing. Over the past week, has the patient usually had problems swallowing pills or eating meals? Do they need their pills cut or crushed or their meals to be made soft, chopped or blended to avoid choking?
   a. Normal: No problems.

   b. Slight: They are aware of slowness in their chewing or increased effort at swallowing, but they do not choke or need to have their food specially prepared.
   c. Mild: They need to have their pills cut or their food specially prepared because of chewing or swallowing problems, but they have not choked over the past week.
   d. Moderate: They choked at least once in the past week.
   e. Severe: Because of chewing and swallowing problems, they need a feeding tube.

17. Eating tasks. Over the past week, has the patient usually had troubles handling their food and using eating utensils? For example, do they have trouble handling finger foods or using forks, knifes, spoons, chopsticks?
   a. Normal: Not at all (No problems).
   b. Slight: They are slow, but they do not need any help handling their food and have not had food spills while eating.
   c. Mild: They are slow with their eating and have occasional food spills. They may need help with a few tasks such as cutting meat.
   d. Moderate: They need help with many eating tasks but can manage some alone.
   e. Severe: They need help for most or all eating tasks.

18. Dressing. Over the past week, has the patient usually had problems dressing? For example, are they slow or do they need help with buttoning, using zippers, putting on or taking off their clothes or jewelry?
   a. Normal: Not at all (no problems).
   b. Slight: They are slow but they do not need help.
   c. Mild: They are slow and need help for a few dressing tasks (buttons, bracelets).
   d. Moderate: They need help for many dressing tasks.
   e. Severe: They need help for most or all dressing tasks.

19. Hygiene. Over the past week, has the patient usually been slow or do they need help with washing, bathing, shaving, brushing teeth, combing their hair or with other personal hygiene?
   a. Normal: Not at all (no problems).
   b. Slight: They are slow but they do not need any help.
   c. Mild: They need someone else to help them with some hygiene tasks.
   d. Moderate: They need help for many hygiene tasks.
   e. Severe: They need help for most or all of their hygiene tasks.

20. Handwriting. Over the past week, have people usually had trouble reading the handwriting of the patient?
   a. Normal: Not at all (no problems).
   b. Slight: Their writing is slow, clumsy or uneven, but all words are clear.
   c. Mild: Some words are unclear and difficult to read.
   d. Moderate: Many words are unclear and difficult to read.

e. Severe: Most or all words cannot be read.

21. Doing hobbies or other activities. Over the past week, has the patient usually had trouble doing your hobbies or other things that you like to do?
    a. Normal: Not at all (no problems).
    b. Slight: They are a bit slow but do these activities easily.
    c. Mild: They have some difficulty doing these activities.
    d. Moderate: They have major problems doing these activities, but still do most.
    e. Severe: They are unable to do most or all of these activities.

22. Turning in bed. Over the past week, does the patient usually have trouble turning over in bed?
    a. Normal: Not at all (no problems).
    b. Slight: They have a bit of trouble turning, but they do not need any help.
    c. Mild: They have a lot of trouble turning and need occasional help from someone else.
    d. Moderate: To turn over they often need help from someone else.
    e. Severe: They are unable to turn over without help from someone else.

23. Tremor. Over the past week, has the patient usually had shaking or tremor?
    a. Normal: Not at all. They have no shaking or tremor.
    b. Slight: Shaking or tremor occurs but does not cause problems with any activities.
    c. Mild: Shaking or tremor causes problems with only a few activities.
    d. Moderate: Shaking or tremor causes problems with many of their daily activities.
    e. Severe: Shaking or tremor causes problems with most or all activities.

24. Getting out of bed, a car, or a deep chair. Over the past week, has the patient usually had trouble getting out of bed, a car seat, or a deep chair?
    a. Normal: Not at all (no problems).
    b. Slight: They are slow or awkward, but usually can do it on their first try.
    c. Mild: They need more than one try to get up or need occasional help.
    d. Moderate: They sometimes need help to get up, but most times they can still do it on their own.
    e. Severe: They need help most or all of the time.

25. Walking and balance. Over the past week, has the patient usually had problems with balance and walking?
    a. Normal: Not at all (no problems).
    b. Slight: They are slightly slow or may drag a leg. They never use a walking aid.
    c. Mild: They occasionally use a walking aid, but do not need any help from another person.

d. Moderate: They usually use a walking aid (cane, walker) to walk safely without falling. However, they do not usually need the support of another person.
e. Severe: They usually use the support of another persons to walk safely without falling.

26. Freezing. Over the past week, on your usual day when walking, does the patient suddenly stop or freeze as if their feet are stuck to the floor.
    a. Normal: Not at all (no problems).
    b. Slight: They briefly freeze but can easily start walking again. They do not need help from someone else or a walking aid (cane or walker) because of freezing.
    c. Mild: They freeze and have trouble starting to walk again, but do not need someone's help or a walking aid (cane or walker) because of freezing.
    d. Moderate: When they freeze they have a lot of trouble starting to walk again and, because of freezing, they sometimes need to use a walking aid or need someone else's help.
    e. Severe: Because of freezing, most or all of the time, they need to use a walking aid or someone's help.

Appendix B

Zarit Burden Interview (ZBI) – Short Version

1. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?
    a. Never
    b. Rarely
    c. Sometimes
    d. Quite frequently
    e. Nearly always

2. Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?
    a. Never
    b. Rarely
    c. Sometimes
    d. Quite frequently
    e. Nearly always

3. Do you feel angry when you are around your relative?
    a. Never
    b. Rarely
    c. Sometimes
    d. Quite frequently
    e. Nearly always

4. Do you feel that your relative currently affects your relationship with family members or friends in a negative way?
    a. Never
    b. Rarely
    c. Sometimes
    d. Quite frequently
    e. Nearly always

5. Do you feel strained when you are around your relative?
    a. Never
    b. Rarely
    c. Sometimes
    d. Quite frequently

e. Nearly always

6. Do you feel that your health has suffered because of your involvement with your relative?
    a. Never
    b. Rarely
    c. Sometimes
    d. Quite frequently
    e. Nearly always

7. Do you feel that you don't have as much privacy as you would like because of your relative?
    a. Never
    b. Rarely
    c. Sometimes
    d. Quite frequently
    e. Nearly always

8. Do you feel that your social life has suffered because you are caring for your relative?
    a. Never
    b. Rarely
    c. Sometimes
    d. Quite frequently
    e. Nearly always

9. Do you feel that you have lost control of your life since your relative's illness?
    a. Never
    b. Rarely
    c. Sometimes
    d. Quite frequently
    e. Nearly always

10. Do you feel uncertain about what to do about your relative?
    a. Never
    b. Rarely
    c. Sometimes
    d. Quite frequently
    e. Nearly always

11. Do you feel you should be doing more for your relative?
    a. Never
    b. Rarely
    c. Sometimes
    d. Quite frequently
    e. Nearly always

12. Do you feel you could do a better job in caring for your relative?
    a. Never
    b. Rarely
    c. Sometimes
    d. Quite frequently
    e. Nearly always

Appendix C

Patient Health Questionnaire-9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems?

1. Little interest or pleasure in doing things?
    a. Not at all
    b. Several Days
    c. More than half the days
    d. Nearly every day

2. Feeling down, depressed, or hopeless?
    a. Not at all
    b. Several days
    c. More than half the days
    d. Nearly every day

3. Trouble falling or staying asleep, or sleeping too much?
    a. Not at all
    b. Several days
    c. More than half the days
    d. Nearly every day

4. Feeling tired or having little energy
    a. Not at all
    b. Several days
    c. More than half the days
    d. Nearly every day

5. Poor appetite or overeating?
    a. Not at all
    b. Several days
    c. More than half the days
    d. Nearly every day

6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down.
    a. Not at all
    b. Several days
    c. More than half the days

   d. Nearly every day

7. Trouble concentrating on things, such as reading the newspaper or watching television.
   a. Not at all
   b. Several days
   c. More than half the days
   d. Nearly every day

8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual.
   a. Not at all
   b. Several days
   c. More than half the days
   d. Nearly every day

9. Thoughts that you would be better off dead, or of hurting yourself.
   a. Not at all
   b. Several days
   c. More than half the days
   d. Nearly every day

10. If you have indicated having been bothered by *any* of these problems, how *difficult* have these problems made it for you to do your work, take care of things at home, or get along with other people?
   a. Not difficult at all
   b. Somewhat difficult
   c. Very difficult
   d. Extremely difficult

Appendix D

Generalized Anxiety Disorder 7-Item (GAD-7)

Over the last 2 weeks, how often have you been bothered by the following problems?

1. Feeling nervous, anxious, or on edge
    a. Not at all
    b. Several days
    c. More than half the days
    d. Nearly every day

2. Not being able to stop or control worrying
    a. Not at all
    b. Several days
    c. More than half the days
    d. Nearly every day

3. Worrying too much about different things
    a. Not at all
    b. Several days
    c. More than half the days
    d. Nearly every day

4. Trouble relaxing
    a. Not at all
    b. Several days
    c. More than half the days
    d. Nearly every day

5. Being so restless that it's hard to sit still
    a. Not at all
    b. Several days
    c. More than half the days
    d. Nearly every day

6. Being easily annoyed or irritable
    a. Not at all
    b. Several days
    c. More than half the days
    d. Nearly every day

7. Being afraid as if something awful might happen
    a. Not at all
    b. Several days
    c. More than half the days
    d. Nearly every day

8. If you indicate being bothered by any of these problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people?
    a. Not difficult at all
    b. Somewhat difficult
    c. Very difficult
    d. Extremely difficult

Appendix E

SCORE-15

For each line, would you say **this describes our family:**	**1. Describes us: Very well**	**2. Describes us: Well**	**3. Describes us: Partly**	**4. Describes us: Not well**	**5. Describes us: Not at all**
1. In my family we talk to each other about things which matter to us	1	2	3	4	5
2. People don't often tell each other the truth in my family	1	2	3	4	5
3. Each of us gets listened to in our family	1	2	3	4	5
4. It feels risky to disagree in our family	1	2	3	4	5
5. We find it hard to deal with everyday problems	1	2	3	4	5
6. We trust each other	1	2	3	4	5
7. It feels miserable in our family	1	2	3	4	5
8. When people in my family get angry they ignore each other on purpose	1	2	3	4	5
9. We seem to go from one crisis to another in my family	1	2	3	4	5
10. When one of us is upset they get looked after within the family	1	2	3	4	5
11. Things always seem to go wrong for my family	1	2	3	4	5
12. People in the family are nasty to each other	1	2	3	4	5
13. People in my family interfere too much in each other's lives	1	2	3	4	5
14. In my family we blame each other when things go wrong	1	2	3	4	5
15. We are good at finding new ways to deal with things that are difficult	1	2	3	4	5

Vita

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