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Relationships Among Parkinson's Disease Symptoms, Stigma, and Mental Health: A Strengths-Based Perspective

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RELATIONSHIPS AMONG PARKINSON'S DISEASE SYMPTOMS, STIGMA, AND MENTAL HEALTH: A STRENGTHS-BASED PERSPECTIVE

A Dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University

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Abstract

RELATIONSHIPS AMONG PARKINSON'S DISEASE SYMPTOMS, STIGMA, AND MENTAL HEALTH: A STRENGTHS-BASED PERSPECTIVE

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As rates of Parkinson's disease (PD) increase, so does the need to examine some of the negative social consequences experienced by people with PD. Symptoms of PD have been linked to greater experiences of stigma, and the more visible symptoms of PD increase an individual's likelihood for experiencing stigmatization and social rejection. Individuals who experience high levels of stigma generally have poorer mental health outcomes. While these relationships are well documented, little is known about whether stigma mediates the relationship between PD symptoms and mental health outcomes. Additionally, some past research suggests that the personal strengths of social support and spirituality may moderate the relationship between stigma and mental health in other populations; however, no research has examined the potential moderating effects of these variables in individuals with PD. This study sought to examine the connections among PD symptoms, stigma, and mental health, as well as examine social support and spirituality as potential buffers. This study represents a secondary data analysis of clinical data reflecting these constructs collected from 392 individuals with PD being seen at a PD specialty clinic affiliated with an academic medical center. Results showed stigma partially mediated the relationship between both motor and non-motor symptoms and mental health

problems. There was also a moderating effect of social support on the relationships among motor/non-motor symptoms, stigma, and mental health problems, with stronger indirect effects at low levels of social support, suggesting that this mediational model held only for individuals with low social support. Spirituality moderated the relationships among motor/non-motor symptoms, stigma, and mental health problems, with stronger indirect effects at lower levels of spirituality, again suggesting that this mediational model held only for those with low or mid-levels of spirituality. Implications of these results are that health professionals working with individuals with PD may wish to consider stigma and discrimination in how they present and design treatment options for PD patients. Interventions designed to increase and foster social support among individuals with PD, such as helping individuals maintain a number of positive close relationships, may have beneficial mental health effects. Also, including an assessment of spiritual practice and beliefs into patient assessments may help health care providers better understand an individual with PD's worldview, and subsequently view of chronic illness, if there is a spiritual community of support, and if spiritual interventions and coping mechanisms may be appropriate and helpful for the individual.

Chapter 1

Overview

This manuscript will begin by discussing the prevalence of Parkinson's disease (PD). To date, the causes of PD are not yet known, and as such there are no definitive diagnostic tests for PD. This is followed by a discussion of PD etiology, the progression of the disease, and attempts at defining different stages of PD. The clinical presentation of PD can vary by the individual, and stages are not always linear. The next section will discuss treatment of PD. Although there are no neuroprotective therapies and no cure for PD, there are some pharmacological therapies aimed at reducing PD symptoms to improve quality of life. It will be illustrated that individuals with PD often experience stigma as a result of the negative social interpretations of the symptomatic movements of PD. The Minority Stress Model will be used to illustrate how stigma may account in part for the relationship between PD symptoms and negative mental health. This is followed by research exploring the protective factors of social support and spirituality for individuals with PD from experiences of stigma. The objectives of the current study will be discussed next followed by the methods, data analysis plan, and a discussion of the potential implications of the results.

Epidemiology

A progressive neurodegenerative disease, Parkinson's disease (PD) over time leads to both cognitive impairment (Petrou, Dwamena, Foerster, MacEachern, Bohnen, Müller, et al., 2015) and physical disability (Shulman et al., 2016). An individual's independent functioning may be limited as a result of these impairments and disabilities. In the United States, PD is the second most common progressive neurodegenerative disease (de Lau & Breteler, 2006). PD affects approximately 1% of individuals over the age of 60 (Nussbaum & Ellis, 2003), and other rates suggest about 1 to 2 individuals per 1,000 (Tysnes & Storstein, 2017). By 2030, an

estimated 1.2 million individuals will be living with PD in the US (Marras et al., 2018). The increases in number of PD cases is due to both proportions of the older adult population with PD increasing and the overall number of older adults in the population increasing (Dorsey & Bloem, 2018; Marras et al., 2018). PD is an age-related disease, with prevalence increasing with age, and onset is rare before the age of 50 (Muangpaisan et al., 2011; Rocca, 2018; Savica et al., 2018). While estimates vary, approximately 1% of adults over the age of 60 are affected by PD in industrialized countries (Nussbaum & Ellis, 2003), this number increases to approximately 2.6% of adults over the age of 85 who are affected (Pringsheim et al., 2014).

Age is a commonly accepted risk factor for PD (Collier et al., 2017). Other potential risk factors include environmental toxins, drugs, pesticides, brain microtrauma, and genetics (Cacabelos, 2017). However, there remains conflicting evidence around a number of risk factors including gender, ethnicity, living circumstances, and occupations (Ball et al., 2019). All these factors have been suspected in heightened PD risk, although the evidence remains conflicted.

Disease Course and Diagnosis

The etiology of PD is still not fully understood, despite ongoing research examining the underlying causes. PD represents multi-level system dysfunction with widespread involvement of other body systems (Caviness, 2014; Ehgoetz Martens & Lewis, 2017). First, cellular and tissue abnormalities occur as a result of genetic influences. As a result of these abnormalities, the dopamine neurons in the substantia nigra region of the brain are damaged, altered, or killed (Caviness, 2014). The resulting decrease in dopamine plays a critical role in the development of the motor symptoms of the disease, and ultimately influences an individual's behavior (Caviness, 2014). Genetic mutations are still not able to explain the majority of PD cases, despite the efforts to identify these mutations (Caviness, 2014; de Lau & Breteler, 2006). As approximately 90% of

PD cases are sporadic (de Lau & Breteler, 2006), there may be other important factors—such as exposure to environmental toxins (Ball et al., 2019; Cacabelos, 2017)—which contribute to the development of PD.

There is not currently a definitive diagnostic test for PD, and as a result PD may be difficult to diagnose due to the similarities it shares with other neurological conditions. While diagnostic certainty is not possible during an individual's life (Postuma et al., 2015), postmortem confirmation of diagnoses using neuropathological criteria may occur (Adler et al., 2019; Gibb & Lees, 1988). Research using postmortem confirmation suggests a diagnostic accuracy which ranges between 75-95% (Hughes, Daniel, Kilford, & Lees, 1992; Hughes, Giobbie-Hurder, Weaver, Kubal, & Henderson, 1999; Litvan et al., 1998; Tolosa, Wenning, & Poewe, 2006). Consequently, a clinical diagnosis of PD is based on the presence of characteristic motor symptoms, how the individual responds to L-Dopa, and additional associated inclusionary and exclusionary symptoms (Rao et al., 2003).

As a progressive condition, there have been many attempts to define and outline the stages and progression of PD (Goetz et al., 2004; Owen et al., 1993; Starkstein, Bolduc, Preziosi, & Robinson, 1989). One of the mostly commonly used systems was outlined by Hoehn and Yahr in which five stages were identified (Hoehn & Yahr, 1967). The first stage generally has unilateral involvement and is characterized by minimal to no functional impairment. The second stage is defined by bilateral involvement; however, balance is usually not impaired. In the third stage, individuals may still be able to take care of themselves, unsteadiness first begins to appear, and individuals may not be able to maintain their balance when standing if pushed. PD is considered fully developed and severely disabling by stage four. Individuals may still be able to stand or walk without assistance at this point. In the fifth stage, individuals are often confined to

a bed or wheelchair. It is important to note that progression through these stages may not always be linear (Poewe, 2006). One example of this is that there are typically greater declines in motor function earlier in the disease than later (Poewe, 2006).

PD itself is not usually fatal; rather, individuals with PD often die of complications from later stages of the disease and comorbidities (Beyer et al., 2001; Bugalho et al., 2019; Paul et al., 2019; Wermuth et al., 1995). PD has several different phenotype varieties, all of which are progressive (Evans et al., 2011). While clinical presentation varies, early physical symptoms may include bradykinesia (slow movements), stiffening muscles, hand tremors, sleep disruption, speech changes, and decreased facial expressivity (Jankovic, 2008; Mosley et al., 2017). Along with the physical symptoms, both early cognitive and emotional changes may occur such as feeling depressed, anxious, or fearful and difficulty concentrating (Weintraub & Burn, 2011). The progression of physical symptoms includes loss of muscle control which may lead to difficulty swallowing, urinary incontinence, and bowel dysfunction (NINDS, 2019). Patients may also experience hallucinations, delusions, and dementia as the disease progresses and during pharmacological treatment (Mosley et al., 2017; Weintraub & Burn, 2011).

Life expectancy of individuals with PD is thought to be reduced (Elbaz et al., 2003; Morens et al., 1996). Individuals with PD will live 15 years post-diagnosis on average (Lees et al., 2009). However, due to treatment advances, some individuals with PD are living even longer (Lee & Gilbert, 2016). Due to the variation in disease progression, disease course may be greatly impacted by age of diagnosis. Studies suggest that individuals who are diagnosed younger tend to live longer post-diagnosis than individuals who are diagnosed when they are older (Ishihara et al., 2007).

Symptoms

The clinical presentation of PD can vary by patient and is very similar to other neurological conditions. Symptoms of PD have been classified by symptom type (e.g., motor aspects of experiences of daily living, non-motor experiences of daily living, cognitive impairment, depressed/anxious mood, etc.) for both diagnostic and research purposes (Goetz et al., 2008; Peto et al., 1998). Motor symptoms, including bradykinesia, postural instability, resting tremor (shaking while in a relaxed state), and akinesia (loss or impaired voluntary movement) have historically been characteristic of PD (Mandir & Vaughan, 2000). Additional motor symptoms may also be present, including reduced facial expression (Ricciardi et al., 2015) and gait issues (Forsaa et al., 2015). While motor Parkinsonism remains a prominent feature of the disease, the non-motor manifestations of PD have received increased attention. Individuals will generally present numerous non-motor symptoms by 10 years post-diagnosis (Poewe, 2006). Non-motor symptoms of PD may include cognitive impairment, apathy, depression, anxiety, sleep disruption, psychosis, and dementia (Mosley et al., 2017).

Treatment

To date, there is no neuroprotective therapy for PD (AlDakheel et al., 2014) and no cure (Connolly & Lang, 2014). There are pharmacological therapies aimed at reducing symptoms to improve quality of life. Pharmacological interventions are usually pursued when individuals with PD experience impairment or embarrassment from their symptoms (Connolly & Lang, 2014). While symptoms are mild, generally in the early stages of the disease, monoamine oxidase type B inhibitors (MAOBIs) such as rasagiline or selegiline might be prescribed to reduce symptoms (Ives et al., 2004). Additionally, in the early stages of PD and once activities of daily living become impaired, dopamine agonists or levodopa (L-dopa) may be effective treatments

(Connolly & Lang, 2014; Fox et al., 2011). L-dopa is one of the most common pharmacological treatments for PD (Mandir & Vaughan, 2000).

Individuals with PD have depleted levels of dopamine in the brain, and the role of L-dopa is to raise dopamine levels (Connolly & Lang, 2014). Administration of L-dopa is typically done in combination with a decarboxylase inhibitor—carbidopa—which prevents the conversion of L-dopa to dopamine and helps maximize the delivery to the brain (Mandir & Vaughan, 2000). L-dopa has been associated with reductions in freezing, somnolence, edema, risk of impulse control disorders, and hallucinations compared to dopamine agonists (Ferreira et al., 2013) and is considered to be one of the most effective pharmacological treatments currently available for PD (Mandir & Vaughan, 2000).

As the disease progresses, PD becomes more resistant to treatment, as non-dopaminergic brain regions are increasingly affected (Connolly & Lang, 2014). The degenerative processes that cause PD are not directly influenced by dopamine treatments (Korczyn & Hassin-Baer, 2015). Pharmacologic interventions for patients have yet to catch-up or benefit from advances in understandings of the genetic contributions, molecular mechanisms, and pathology of PD (Suchowersky et al., 2006). Additionally, while PD symptoms may be decreased using dopamine agonists and L-dopa, there are many potential side effects. Adverse side effects from the medications may include dyskinesias (i.e., involuntary muscle movements), nausea, psychosis, dopamine dysregulation syndrome, impulsive behaviors (Connolly & Lang, 2014).

Stigma in PD

Individuals with PD often experience stigma as a result of the negative social interpretations of the symptomatic movements such as rigidity, reduced facial expressions, and tremors (Moore & Knowles, 2006). Goffman defined stigma as “the situation of the individual

who is disqualified from full social acceptance" (1963, pg. 3). An individual once stigmatized becomes discounted and tainted, no longer a whole person (Goffman, 1963). In addition to being stigmatized for symptomatic movements of PD, PD symptoms are often mistaken for other stigmatized conditions. For example, movement disorders may be misinterpreted as drunkenness, or difficulty in speech or communication may be mistaken for an intellectual disability (Moore & Knowles, 2006). Greater risk of stigmatization and social rejection occur with more visible PD symptoms (Hermanns, 2013). Individuals with PD employ a number of strategies to hide their symptoms and avoid stigmatization, by reducing communication or placing their hands in their pockets (Burgener & Berger, 2008; Hermanns, 2013). In several studies, both the general public and medical professionals across cultures (Taiwan and the US) rated individuals with PD as less friendly, happy, and social due to speech production difficulties and facial masking symptoms (Hemmesch et al., 2009; Jaywant & Pell, 2010; Tickle-Degnen et al., 2011). Awareness of stigmatization and negative interpretations of the PD symptoms by individuals with PD may result in isolation and social withdrawal behaviors (Burgener & Berger, 2008). PD stigma has been significantly correlated with negative quality of life (Ma et al., 2016).

Stigmatization of individuals with PD have been directly linked to PD symptoms. These symptoms include facial masking (Gunnery et al., 2015; Hemmesch, 2014; Hermanns, 2013), dystonias, akinesia (Chapuis et al., 2004), restless leg syndrome (Fereshtehnejad et al., 2015), postural instability, bradykinesia, rigidity, and tremors (Lyons et al., 1997). It has been suggested that stigma often arises from PD motor symptoms, as these symptoms are viewed by others as signs of fragility (Maffoni et al., 2017). Increased rates of depression, anxiety, and negative self-image have also been linked to experiences of stigma in PD (Hatzenbuehler et al., 2013; Mak et al., 2007; Meyer, 2003; Pascoe & Smart Richman, 2009). Previous research in general

populations has found strength-based factors, for example coping and resilience, weakened the strength of associations between stigma and adverse mental health outcomes (Bockting et al., 2013; Hatzenbuehler et al., 2013; Meyer, 2003); however, these relationships have not been examined in the context of PD. To date, very few studies have examined the psychosocial strengths of patients with PD to decrease experiences of stigma, improve mental health outcomes, and improve adjustment to the diagnosis. A better understanding of strength-based factors and their relationship to stigma may improve quality of life in individuals with PD and possibly their daily functioning.

Mental Health and PD

Apathy, anxiety, and depression are extremely common among individuals with PD (Kano et al., 2011; Pagonabarraga et al., 2015; Quelhas & Costa, 2009). A formal clinical diagnosis of PD may only occur once motor symptoms are present. It was originally thought non-motor symptoms (NMS) only occurred in later stages, but it is now known they may be manifest at any stage (Kano et al., 2011). Previous research suggests that anxiety may be present very early in the disease, a finding which held even when examining medical histories up to 20 years prior to the first motor symptom (Kano et al., 2011). These mental health issues can be exacerbated by stigma experienced as a result of having PD (Oguru et al., 2010). Comorbid mental health diagnoses can strongly negatively impact the quality of life of individuals with PD and that of their caregivers (Brok et al., 2015; Kano et al., 2011; Quelhas & Costa, 2009).

Apathy. Apathy is considered a behavioral syndrome which has behavioral, cognitive, and affective features and is defined by decreased motivation, reduced interests or emotions, and decreased goal-directed behaviors which cannot be attributed to other cognitive impairment or emotional distress (Pagonabarraga et al., 2015). Maintenance of motivation is attributed to

subcortical structures, specifically the link between the limbic system and prefrontal cortex. Disruption of these networks, as occurs in PD, alters the ability to associate complex stimuli with emotions (Pagonabarraga et al., 2015). Apathy is the clinical manifestations of these changes. Along with apathy being clinically significant to PD, motivation is an important psychological feature to overall mental well-being. Motivation promotes goal-driven behaviors and sustaining those goal-directed behaviors (Pagonabarraga et al., 2015). An absence of self-initiated goal-directed behaviors as seen in apathy is sometimes described as an indifference or flattening of affect (Pagonabarraga et al., 2015).

There is a high prevalence of apathy in PD which can greatly influence the quality of life of both individuals with PD and their caregivers (Pagonabarraga et al., 2015). Apathy is seen in approximately 20-36% of newly diagnosed individuals, with a decrease among those subsequently treated with dopaminergic treatments (Pagonabarraga et al., 2015). The prevalence of apathy is higher among PD patients with dementia (60% vs 40%, 5-10 years post diagnosis) (Pagonabarraga et al., 2015). A meta-analysis found an overall prevalence of about 40%, with apathy present without depression or cognitive impairment in half of cases (Brok et al., 2015). Apathy was also associated with more severe disability, older age, increased motor symptoms, depression, worse cognitive function, and potentially lower quality of life and increased caregiver burden (Brok et al., 2015). Previous research has also shown that apathy is strongly associated with stigma and cognitive symptoms (Oguru et al., 2010).

Apathy is frequently seen in PD, as a unique symptom or syndrome independent of depression—although it is conventionally considered a clinical symptom of depression. A review of apathy found three possible explanations for apathy in PD (Bogart, 2011). First, research has suggested links among dopamine depletion and basal ganglia dysfunction in PD and apathy—an

endogenous explanation. Second, activity restriction and disability from PD may lead to apathy—an exogenous explanation. Finally, methodological confounds and conceptual problems may be obscuring the relationship between apathy and PD (Bogart, 2011). However, as one of the most debilitating and common non-motor manifestations of PD (Martínez-Horta et al., 2014; Starkstein, 2012), for the purposes of this study, apathy will be included as a mental health outcome given its potential to add a heavy burden for the individual with PD and potential to operate differently than either depression or anxiety.

Anxiety. In PD, the most common anxiety disorders include panic disorder, phobic disorder, social phobia, and generalized anxiety disorder (Kano et al., 2011; Pontone et al., 2009; Walsh & Bennett, 2001). Anxiety is characterized by worry, fear, and apprehension (Kano et al., 2011). Clinically significant anxiety prevalence is estimated in between 25% to 40% of individuals with PD (Kano et al., 2011; Pontone et al., 2009; Quelhas & Costa, 2009; Starkstein, Robinson, Leiguarda, & Preziosi, 1993; Walsh & Bennett, 2001). It has been posited that anxiety may be a response to the PD symptoms (Walsh & Bennett, 2001). There are several factors which may perpetuate anxiety throughout the disease course, including worrying about the risk of falls and disturbances in balances and unexpected fluctuations in symptoms, as well as social anxiety, a fear of negative evaluation in public (Walsh & Bennett, 2001). For example, individuals may become self-conscious or embarrassed by their motor impairments such as their stooped posture, shuffling gait, and tremor (Quelhas & Costa, 2009). This negative evaluation may also be stigmatization, the consequences of which may include anxiety and social withdrawal. Anxiety has been significantly associated with decreased quality of life among individuals with PD, perhaps even more so than depression (Kano et al., 2011; Pontone et al., 2009; Quelhas & Costa, 2009).

Depression. Clinical depression includes consistent symptoms for at least a two week period in which an individual has a depressed mood, loss of interest or pleasure in daily activities, fatigue, weight loss, and insomnia (Kano et al., 2011). The prevalence of depression is estimated between 4% to 70%, although common ranges are between 30-45% of individuals with PD will experience clinically significant depression (Quelhas & Costa, 2009). Variation in estimates may be the result of how depression is being measured and the specific PD population being surveyed. Previous studies have correlated depression with duration of illness, severity of impairments, and cognitive deficits (Starkstein et al., 1993). Research suggests that depression is a main factor related to negative quality of life for individuals with PD (Quelhas & Costa, 2009).

Strength-Based Factors

There has been limited research with individuals with PD exploring the strength-based, protective factors of social support and spirituality. However, research in both general and PD populations has demonstrated that social support and spirituality may protect against a variety of mental health problems (Brod et al., 1998; Reynolds, 2017), stigma, and decreased quality of life (Reynolds, 2017; Schrag et al., 2003).

Social Support. Social support is not well understood for individuals with PD, and is most often studied in conjunction with depression (Schreurs et al., 2000). Studies of social support for individuals with PD generally examine one's perceptions of support from others, such as support from family and friends or difficulties in close relationships (Peto et al., 1995, 1998). However, for both PD and other chronic illnesses, some studies have shown that social support from close relationships does not differ as a function of disease severity (Fitzpatrick, Peto, Jenkinson, Greenhall, & Hyman, 1997; Fitzpatrick, Newman, Lamb, & Shipley, 1988). Individuals with PD who are less satisfied with their social relationships and experience lower

social support are more likely to experience higher rates of anxiety, depression, stress, and decreased quality of life (Brod et al., 1998; Fleminger, 1991; Simpson et al., 2006; Takahashi et al., 2016). Social support has also been associated with positive well-being (e.g., happiness), suggesting that it is not just psychological distress but well-being that may be influenced by social support (MacCarthy & Brown, 1989). A study by Schrag and colleagues (2003) compared age of PD onset, and individuals with younger onset PD experienced greater disruption of their family and social lives and higher rates of perceived stigmatization.

Spirituality. Spirituality has been identified in extant literature as a form of coping with chronic illness (Reynolds, 2017), which includes individuals with PD. Research has demonstrated that individuals with a spiritual life and/or committed religious orientation tend to have lower rates of depression and anxiety, better ability to cope, and greater overall quality of life (Harris et al., 2010; Reynolds, 2017; Rowe & Allen, 2004; Shafranske & Malony, 1990; Unantenne et al., 2013). However, the research focused on spiritual coping for PD is extremely limited. Spirituality often refers to purpose, meaning, transcendence, connectedness, or direction, although a precise and universal definition is not agreed upon (Reynolds, 2017). Spiritual coping for individuals with PD may include using spirituality to cope with their disease, accepting and adjusting to their diagnosis, and maintaining hope (Soundy et al., 2014). For some, the ritual of prayer is also utilized for healing, managing the disease, and in making decisions (Soundy et al., 2014). In a qualitative study of 56 PD patients, five themes related to spiritual coping emerged: (1) feeling a sense of gratitude; (2) connecting with individuals; (3) depending on faith; (4) providing meaning to PD; and (5) prayer (Reynolds, 2017). Using spirituality for coping is not just limited to living with a chronic illness, but can also assist with other health-related challenges including apathy, anxiety, depression, and stigma (Hermanns, 2013; Reynolds, 2017).

Theoretical Model

A very common theoretical framework for explaining stigma and health risks is the Minority Stress Model (Meyer, 2003). This framework was developed to explain sexual minority health disparities through their experiences of chronic stress, hostility, harassment, victimization, and discrimination (Meyer, 2003). In other words, the chronic, unique, and socially based stressors faced by sexual minorities related to their identities will negatively impact their mental health (Meyer, 2003). This model includes a variety of stressors and coping mechanisms and the resulting mental health outcomes (Meyer, 2003). While this framework was originally developed and validated in a sexual minority adult population, it has been adapted for a variety of minority populations (Meyer et al., 2008) including individuals with general disabilities (Conover & Israel, 2019).

The Minority Stress Model can be used to assess a variety of relationships related to the experiences of individuals with PD. Symptoms of PD lead to individuals with PD experiencing stigma and discrimination (Moore & Knowles, 2006). Individuals with PD also experience high rates of apathy, anxiety, and depression (Kano et al., 2011; Pagonabarraga et al., 2015; Quelhas & Costa, 2009). Previous research in other populations has documented that experiences of discrimination are predictive of higher levels of mental health issues (Burgener & Berger, 2008; Maffoni et al., 2017; Sutter & Perrin, 2016). Additionally, there is some evidence that social support and spirituality may be able to mitigate the link between discrimination and mental health, although these effects have not been documented in people with disabilities (Brewster et al., 2016; Ojeda & Piña-Watson, 2013).

The Current Study

As the prevalence of PD increases, so does the need to examine some of the negative social consequences. Previous literature has linked symptoms of PD to increased experiences of stigma (Moore & Knowles, 2006). Experiences of stigma may result in PD patients withdrawing socially and isolating themselves (Burgener & Berger, 2008), which ultimately may lead to poorer mental health outcomes (Hatzenbuehler et al., 2013; Mak et al., 2007; Meyer, 2003; Pascoe & Smart Richman, 2009). Despite the clear correlations among symptoms, stigma, and mental health problems, there is relatively little research examining the potential mediation effect of stigma on the relationship between symptoms and poor mental health. Specifically, mood and motor symptoms have been linked, such that as motor symptoms decline so do mood symptoms (Marsh, 2013). Additionally, relatively little research has examined the roles of social support and spirituality as protective factors. Therefore, the purpose of this study was to examine the connections among PD symptoms (motor and non-motor), stigma, and mental health problems, as well as examine whether social support and spirituality moderated these relationships.

Hypothesis 1: Research has linked various types of PD symptoms with stigma (Moore & Knowles, 2006). Accordingly, it was hypothesized that increased PD symptoms (motor and non-motor) will be associated with higher levels of stigma.

Hypothesis 2: Previous research has demonstrated a link between stigma with increased apathy, anxiety, and depression (Hatzenbuehler et al., 2013; Meyer, 2003; Oguru et al., 2010). Therefore, it was hypothesized that stigma will be associated with higher levels of mental health issues (i.e., apathy, anxiety, and depression).

Hypothesis 3: There is research linking PD symptoms and stigma for individuals with PD (Moore & Knowles, 2006). There have also been relationships between stigma and mental

health issues (Hatzenbuehler et al., 2013; Meyer, 2003; Oguru et al., 2010). Given these previously uncovered relationships, it was hypothesized that stigma will mediate the relationship between PD symptoms (motor and non-motor) and mental health (i.e., apathy, anxiety, and depression).

Hypothesis 4: There has been limited research exploring relationships among social support, PD symptoms, stigma, and mental health in individuals with PD. However, research has demonstrated that social support may protect against a variety of mental health problems (Brod et al., 1998; Simpson et al., 2006), stigma (Schrag et al., 2003), and decreased quality of life (Takahashi et al., 2016). Based upon the literature review, it was hypothesized that social support will moderate relationships among PD symptoms (motor and non-motor), stigma, and mental health problems, such that higher levels of social support will weaken these relationships.

Hypothesis 5: Research with individuals with PD has not explored relationships among spirituality, PD symptoms, stigma, and mental health problems. However, research has demonstrated that spirituality may protect against a variety of mental health problems, stigma, and decreased quality of life (Hermanns, 2013; Reynolds, 2017). It was therefore hypothesized that spirituality will moderate the relationships among PD symptoms (motor and non-motor), stigma, and mental health, such that higher levels of spirituality will weaken these relationships.

Chapter 2

Methods

Participants

Participants (N = 392) were Parkinson's disease (PD) patients at a multidisciplinary PD clinic in a public, academic medical center in the Mid-Atlantic region of the US. To be eligible to participate in the study, PD patients had to: (a) be enrolled in the clinic's research registry, (b) have a physician diagnosis of PD, (c) have baseline (first appointment data), (d) be over the age of 18, and (e) be able to read and respond in English. Individuals were ineligible to participate if: (a) their primary diagnosis was any non-PD movement disorder diagnosis or unknown clinical movement disorder or (b) they had comorbid psychiatric and neurologic diagnoses such as bipolar disorder, schizophrenia, epilepsy, or head injury.

Demographic information for participants appears in Table 1. The sample was predominately White, male, and with at least some college education. While the mean age was nearly 70 years old, the youngest participant was 36 and oldest was 88.

Table 1. *Sample Characteristics*

Characteristics	(N = 392)
Age, *M* (*SD*)	68.11 (8.78)
Race/Ethnicity *n* (%)	
Caucasian/White	357 (91.1)
African American/Black	25 (6.4)
Hispanic/Latino	3 (0.8)
Asian	3 (0.8)
Middle Eastern	1 (0.3)
Indian	2 (0.5)
Native American	1 (0.3)
Sex n (%)	
Female	141 (36.0)
Male	251 (64.0)
Years of Education, *M* (*SD*)	15.24 (2.97)

A post-hoc power analysis was conducted to determine if the proposed analyses would be adequately powered given the sample size. Using G*Power 3.1 (Faul et al., 2007), for a moderated mediation (the analysis with the greatest number of parameters with five predictors and one criterion variable) a sample size of 392, a .05 alpha level, and power at .80 (1-β), the current sample size would be able to identify all large-, medium-, and small-sized effects $\geq$ f = .04.

Procedure

A research registry was queried for all individuals with PD's first neuropsychological evaluation who meet the study inclusion criteria. These individuals had undergone a neuropsychological evaluation at the multidisciplinary PD clinic between 2011 and 2019 and consented to have their data included into the clinic's research registry for ongoing and future research. As part of the clinical neuropsychological evaluation, individuals with PD completed pencil and paper self-report measures examined in the current study in private clinic rooms. The neuropsychological evaluation varied by clinician; as such, individuals included in the registry may have being assessed using different measures of the same construct. PD symptoms, stigma, and social support were assessed through the Parkinson's Disease Questionnaire-39. PD symptoms were also assessed via the Non-Motor Symptoms Questionnaire (PD-NMS). Apathy was measured using the Apathy Scale. Anxiety was measured using the Generalized Anxiety Disorder-7 or Beck Anxiety Inventory, depression was measured using the Patient Health Questionnare-9, Beck Depression Inventory-II, or Geriatric Depression Scale-Short Form, and spirituality was assessed using one item of the Linear Analogue Self-Assessment. A variety of demographic information was also obtained including age, race/ethnicity, gender, education,

marital status, work status and work history. The study was approved by the institution's ethical review board.

Measures

In order to create indices of motor and non-motor symptoms and mental health, measures reflecting these constructs were comprised of items from several PD and mental health questionnaires. This section will first describe the questionnaires themselves and then describe the process for identifying the specific items for inclusion and exclusion, as well as the combination process.

Parkinson's Disease Questionnaires-39 (PDQ-39). The PDQ-39 was used to assess PD symptoms, stigma, and social support (Peto et al., 1998). The stigma and social support subscales were used. The remaining items were evaluated and sorted into motor and non-motor symptom categories as described below. Subscale scores (included motor and non-motor symptoms) were obtained by totaling the raw score, dividing by the total number of items in the subscale, and multiplying by 100. Scores range from 0 (no problem at all) to 100 (maximum possible score) for each subscale, with higher scores representing greater symptoms, higher stigma, or lower social support. In a validation study of the PDQ-39, internal validity was acceptable or better for all subscales (expect social support at time one; $\alpha = .76$), and the internal reliability for the total score was good ($\alpha = .84, .89$) across two clinical samples (Peto et al., 1998). In the current study, the internal reliability of the total scale was excellent ($\alpha = .96$); by subscales the internal reliability of mobility ($\alpha = .94$), cognitions ($\alpha = .73$), bodily discomfort ($\alpha = .73$), activities of daily living ($\alpha = .89$), emotional well-being ($\alpha = .90$), stigma ($\alpha = .87$), and social support ($\alpha = .74$) were acceptable to excellent.

Non-Motor Symptoms Questionnaire (NMS). Symptoms of PD were also assessed using the 30-item NMS (Martinez-Martin et al., 2007). Individuals are presented a range of possible problems they may have experienced in the previous month and asked to respond "yes" or "no" as to whether they have experienced the symptom. Each "yes" response is given a value of one and a total score is calculated, with higher scores representing more severe symptoms. Items were evaluated and sorted into motor and non-motor symptom categories as described below. Internal reliability averaged across nine domains was questionable ($\alpha = .61$) in a pilot study (Chaudhuri et al., 2007). In the current study, the internal reliability of the scale was good ($\alpha = .81$).

Apathy Scale (AS). Apathy was assessed using the 14-item AS (Starkstein et al., 1992). Items use a four-point Likert-type scale, with total scores ranging from 0 to 42. Higher scores represent higher apathy. A score of 14 or higher indicates clinically significant levels of apathy in PD. This scale had acceptable internal reliability ($\alpha = .76$) in validation studies with PD patients (Starkstein et al., 1992). In the current study, the internal reliability of the full scale was good ($\alpha = .80$), and with two excluded items was acceptable ($\alpha = .77$).

Generalized Anxiety Disorder-7 (GAD-7). Anxiety was assessed using the GAD-7 (Spitzer et al., 2006). Individuals use a Likert-type scale ranging from 0 ("not at all") to 3 ("nearly every day") to respond to seven items. Total scores are summed with possible scores ranging from 0 to 21. Scores of 0 to 4 indicate minimal severity, 5 to 9 mild severity, 10 to 14 moderate severity, and 15 to 21 severe anxiety. This scale had excellent internal reliability ($\alpha = .92$) in a validation study of primary care clinic patients (Spitzer et al., 2006). In the current study, the internal reliability of the full scale was excellent ($\alpha = .91$).

Beck Anxiety Inventory (BAI). Anxiety was also be assessed using the BAI (Beck, Epstein, Brown, & Steer, 1988). The 21-item scale response options range from 0 ("not at all) to 3 ("severely – it bothered me a lot"). Scores of 0-7 reflect minimal anxiety, 8-15 mild anxiety 16-25 moderate anxiety, and 26-63 severe anxiety. This scale has excellent internal reliability (α = .92) in a validation study of psychiatric outpatients (Beck, Epstein, Brown, & Steer, 1988). In the current study, the internal reliability of the full scale was good (α = .88), and with nine excluded items was good (α = .83).

Beck Depression Inventory-II (BDI-II). Depression was assessed using the BDI (Beck, Steer, & Brown, 1996; Dozois, Dobson, & Ahnberg, 1998). This 21-item self-report measure has response items on a four-point scale. Scores of 0-13 indicate minimal depression, 14-19 mild, 20-28 moderate, and 29-63 severe. This scale has excellent internal consistency among college students (α = .93) and clinical outpatients (α = .92) (Beck et al., 1996; Dozois et al., 1998). In the current study, the internal reliability of the full scale was excellent (α = .90), and with three excluded items was excellent (α = .90).

Patient Health Questionnare-9 (PHQ-9). Depression was measured using the PHQ-9 (Kroenke et al., 2001). Responses to this nine-item measure are on a Likert-type scale ranging from 0 ("not at all") to 3 ("nearly every day"). Total scores are summed, with 5 to 9 indicating mild, 10 to 14 moderate, 15 to 19 moderately severe, and 20 to 27 severe depressive symptomatology. This scale had good internal reliability (α = .89) in a validation study of primary care clinic patients (Kroenke et al., 2001). In the current study, the internal reliability of the full scale was good (α = .86), and with two excluded items was good (α = .84).

Geriatric Depression Scale Short Form (GDS-SF). The GDS-SF was also be used to assess depression (Sheikh & Yesavage, 1986). This scale is a 15-item self-report measure with

"yes/no" response options. Scores of 0-4 are normal, 5-8 mild, 8-11 moderate, and 12-15 severe depression. This scale had excellent internal reliability (α = .92) in a study of Parkinson's patients (Ertan et al., 2005). In the current study, the internal reliability of the full scale was good (α = .85), and with one excluded item was good (α = .84).

Linear Analogue Self-Assessment (LASA). Spirituality was assessed using the LASA (Locke et al., 2007). The LASA comprises of five quality of life items—including spirituality—with functioning of each rated on zero to ten scale (zero being the worst, ten being the best). Only the single spirituality item will be used for this study.

Measure Screening

The motor and non-motor symptom measures were composed of items from both the PDQ-39 and NMS. Duplicate items were screened for across the PDQ-39 and NMS. Using current PD criteria of motor and non-motor symptoms and clinician review, items were coded as either motor or non-motor. Four duplicate items were found, and the NMS items were retained, as the PDQ-39 are often considered quality of life measures. Six items from the PDQ-39 were eliminated as they overlapped with mental health constructs. This left 21 items other than the stigma and social support items. One item was rejected because it did not fit clear symptom categories and appeared to more closely approximate the stigma items. This left 16 items that were coded as motor and four non-motor from the PDQ-39. From the NMS, three items were coded as motor based on clinician review, and 22 were coded as non-motor. Three items were excluded for duplicating mental health constructs, and two were excluded for not clearly fitting into motor or non-motor categories. Overall, 19 items were coded as motor and 26 non-motor. For scoring purposes, items were converted into z-scores and summed.

The mental health composite variable was the average of completed mental health scores including the apathy z-score, anxiety z-score (averaged if both measures completed), and depression z-score (averaged across completed measures). To be included, participants had to have completed at least two of three mental health domains (i.e., apathy, anxiety, and depression). The mental health measures all had the physical health and PD symptoms removed, which resulted in nine items being excluded from the BAI, three from the BDI-II, two from the PHQ-9, and one from the GDS-SF. The mental health scales were also examined for overlapping constructs, which resulted in two items being excluded from apathy.

Data Analysis Plan

In addition the eligibility criteria, data was further screened whereby individuals must have completed (a) at least 50% of items by subscale for the PDQ-39, (b) at least two out of three indices of mental health with at least 50% of items completed, (c) at least 50% of items completed on the NMS. A Little's missing completely at random (MCAR) test was run to examine if data is missing at random. Following the MCAR test, missing data was imputed using expectation maximization.

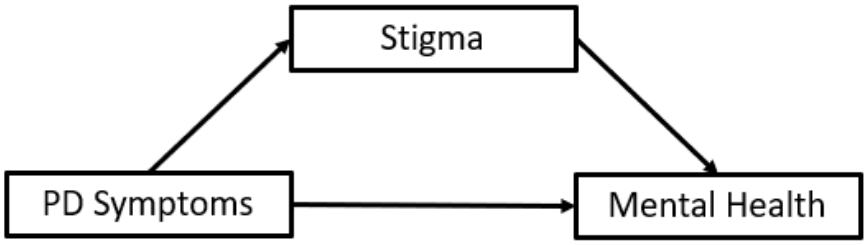
Preliminary Analyses. Prior to conducting the primary statistical analyses to investigate the study's hypotheses, normality tests (i.e., skewness and kurtosis) were performed to establish if the study scales and subscales are distributed normally. Skewness and kurtosis were identified using a critical value of 2.0. If abnormal distributions are detected, data transformation were employed where appropriate for corrections. Multicollinearity was assessed via correlation coefficients among all independent variables (with a goal of $r < .70$ among all predictors).

Primary Analyses. Two base mediations and four moderated mediation models were developed using the PROCESS macro (Hayes, 2017). In the mediation models (Model 4), motor or non-

motor PD symptoms were specified to lead to stigma, which was then specified to lead to a composite (average z-score) mental health variable comprised of apathy, anxiety, and/or depression; see Figure 1). The mediations were examined differentially as a function of participants' social support and spirituality (Model 59; Figure 2). To address H1 and H2, the direct effects of PD symptoms to stigma and stigma to mental health problems were examined (see Figure 1).

Figure 1

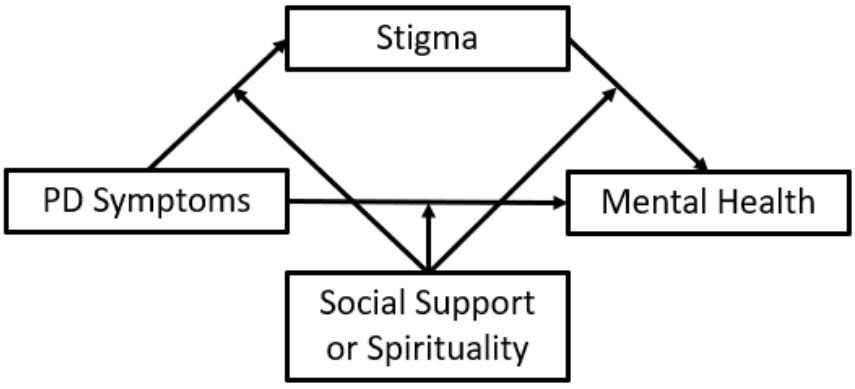
Conceptual Model of Proposed mediation of PD Symptoms, Stigma, and Mental Health Problems



To address H3, the indirect effects of PD symptoms to mental health problems through stigma was examined (see Figure 1). The interactions of the moderated mediations (social support and spirituality; see Figure 2) were examined to address H4 and H5.

Figure 2

Conceptual Model of Proposed moderated mediation of PD Symptoms, Stigma, and Mental Health Problems by Social Support or Spirituality



To identify unique contributions among patterns of connections among PD symptoms, stigma, and mental health problems in individuals with PD, a series of simultaneous multiple regressions were performed. The first regression included the motor and non-motor PD symptoms as the predictors and stigma as the criterion variable. The second through fourth regressions included motor and non-motor PD symptoms as the predictors and mental health problems (i.e., one each for apathy, anxiety, and depression) as the criterion variable. For any demographic variable shown in a correlation matrix to be associated with an outcome, that demographic variable was controlled for in the regression models.

Results

Preliminary Analyses

Data cleaning. In addition the eligibility criteria, data was further screened whereby participants must have completed (a) at least 50% of items by subscale for the PDQ-39, (b) at least two out of three indices of mental health with at least 50% of items completed, (c) at least 50% of items completed on the NMS. To determine whether data were missing at random, a Little's missing completely at random (MCAR) test was conducted. Data were determined to be missing at random for apathy (three missing; p = .925), BAI (five missing; p = .519), and GAD-7 (one missing; p = .288); however, not for the PHQ-9 (p =.001), from which only two responses were missing. There were no missing data in the PDQ-39, NMS, BDI-II, and GDS-SF. Following the MCAR test, missing item-level data were imputed using expectation maximization within the same scale.

Normality and multicollinearity assumptions. Normality tests (i.e., skewness and kurtosis) were performed to establish if the study scales and subscales were distributed normally. Skewed or kurtotic variables were identified using a critical value of +/- 2.0 (see Table 2).

Table 2. *Skewness and Kurtosis Statistics for Study Variables*

Variable	Skewness	Kurtosis
Motor Symptoms	1.12	0.63
Non-motor Symptoms	0.82	0.76
Stigma	1.77	3.05
Mental Health Problems	1.03	1.37
Social Support	-2.25	5.62
Spirituality	-1.06	1.02

Most variables were generally within the cutoff or slightly above for both skewness and kurtosis, social support was very kurtotic. Data transformations were attempted; however, the original variable was retained as attempts at transformations only increased how kurtotic the variable was. Next a correlation matrix was created with all variables (see Table 3).

Table 3. *Correlations of Primary Study Variables*

	1	2	3	4	5
1. Motor Symptoms					
2. Non-motor Symptoms	.610**				
3. Stigma	.478**	.402**			
4. Social Support	-.426**	-.522**	-.445**		
5. Spirituality	-.287**	-.363**	-.273**	.383**	
6. Mental Health Problems	.475**	.592**	.439**	-.450**	-.528**

Note. ** $p < .01$

Additionally, a correlation matrix was created to examine bivariate relationships among demographic variables (age, sex, and years of education) and study variables (see Table 4).

Table 4. *Correlation Matrix with Demographic Variables*

Variable	Age	Sex (0 = female, 1 = male)	Education
Motor Symptoms	.110*	-.078	-.186**
Non-motor Symptoms	-.079	-.151**	-.144**
Stigma	-.277**	-.050	-.108*
Social Support	.111*	.099*	.023
Spirituality	.048	.061	-.008
Mental Health Problems	-.100*	-.068	-.219**

Note. *$p < .05$, **$p < .01$

No data exceeded the threshold ($r < .70$ among all predictors) for multicollinearity via correlation coefficients among all independent variables.

Motor symptoms were positively correlated with non-motor symptoms. Both symptoms types were positively correlated with stigma and mental health problems, and negatively correlated with social support and spirituality. Stigma was negatively correlated with social support and spirituality, and positively correlated with mental health problems. Social support and spirituality were positively correlated with each other, and both negatively correlated with mental health problems. Age was positively associated with motor symptoms and social support, and negatively associated with stigma and mental health problems. Sex was negatively associated with non-motor symptoms such that females reported more non-motor symptoms, and positively associated with social support such that males reported higher levels of social support. Education was negatively correlated with motor symptoms, non-motor symptoms, stigma, and mental health problems.

Outliers. The database was checked for univariate and multivariate outliers. To assess for univariate outliers, the motor symptoms, non-motor symptoms, stigma, mental health composite, spirituality, and social support variables were all converted into z-scores. A cutoff of =/- 3.0 was used to identify univariate outliers. Only stigma (2.6%) and social support (2.8%) exceeded the 1% recommendation for retention by Cohen et al. (2003). As the outliers were not extreme, had reasonable values, and still a small proportion of the sample, all the data were retained.

To identify multivariate outliers, Mahalanobis distance (D^2) was computed. With five degrees of freedom and at $\alpha = .001$, the critical value for detecting multivariate outliers was +/- 20.515. Three multivariate outliers were identified, with the following critical values: 31.587, 29.243, and 27.796. These participants responses were reviewed again, and although extreme,

they were generally consistent with expected patterns. For example, the person with the highest Mahalanobis distance had high symptoms, high stigma, high mental health problems, and low social support. As the three multivariate outliers generally fell within expected patterns without appearing otherwise random or problematic, their scores were retained.

Descriptive statistics. The descriptive statistics (i.e., means, standard deviations) of participants' symptoms, stigma, mental health (apathy, anxiety, and depression), social support, and religious well-being appear in Table 5.

Table 5. *Means and Standard Deviations for Study Variables.*

Variable	N	Mean (SD)	Range
Motor symptoms	392	9 (5.4)	0-19
Non-motor symptoms	392	9 (4.4)	0-23
Stigma	392	16.20 (21.20)	0-100
Social Support	392	90.10 (17.03)	8.33-100
Spirituality	349	7.77 (2.02)	0-10
Apathy	390	11.60 (5.92)	0-34
Anxiety			
BAI	274	9.68 (7.67)	0-40
GAD-7	158	4.28 (4.92)	0-21
Depression			
BDI	287	9.69 (7.61)	0-45
PHQ-9	155	6.26 (5.52)	0-25
GDS-SF	70	4.19 (3.58)	0-14

Note. The means and ranges reflect all items in the original measure.

Based on the clinical cutoff of 14 for apathy, 30.5% of individuals had significant levels of apathy. Of those who completed the BAI, 43.8% had minimal anxiety, 37.2% had mild anxiety, 14.2% had moderate anxiety, and 4.7% severe anxiety. Of those who completed the GAD-7, 65.2% had minimal, 20.9% had mild, 8.2% had moderate, and 5.7% had severe anxiety. Of those who completed the BDI-II, 76.0% had minimal, 13.9% had mild, 7.3% had moderate, and 2.8% had severe depression. Of those who completed the PHQ-9, 28.4% had mild, 12.3% had moderate, 5.8% had moderately severe, and 4.5% had severe depression. Of those who

completed the GDS-SF, 61.4% were in the normal range, 27.1% mild and 11.5% moderate, and nobody scored in the severe depression range.

Primary Analyses

Two base mediation models expanded into four moderated mediation models were developed using the PROCESS macro (Hayes, 2017). In these models, motor or non-motor PD symptoms were specified to lead to stigma, which was then specified to lead to a composite (z-score average) mental health variable comprised of apathy, anxiety, and depression. The mediations were examined differentially as a function of participants' social support and spirituality (Figure 2).

Mediations: The Hayes PROCESS macro was used to conduct two meditational models (Model 4) to examine patterns of relationships that emerged among the primary study variables. In the first mediation, motor PD symptoms was specified to have a direct effect on mental health problems, as well as an indirect effect through stigma, using 5,000 bootstrap samples. The direct paths from motor PD symptoms to stigma (b = .037, p < .001) and from stigma to mental health problems (b = .204, p < .001) were both statistically significant. Further, the indirect effect of motor PD symptoms on mental health problems through stigma was statistically significant (b = .008, 95% CI [.004, .012]), indicating a partial mediation because the direct path from motor PD symptoms to mental health problems was still statistically significant in the model (b = .020, p < .001).

For the second mediation, non-motor PD symptoms was specified to have a direct effect on mental health problems, as well as an indirect effect through stigma, using 5,000 bootstrap samples. The direct paths from non-motor PD symptoms to stigma (b = .038, p < .001) and from stigma to mental health problems (b = .178, p < .001) were both statistically significant. Further,

the indirect effect of non-motor PD symptoms on mental health problems through stigma was statistically significant (b = .007, 95% CI [.003, .011]), indicating a partial mediation because the direct path from non-motor PD symptoms to mental health problems was still statistically significant in the model (b = .035, p < .001).

Moderated mediation: Motor PD symptoms as predictor and social support as moderator. In the first moderated mediation (Model 59), motor PD symptoms was specified to have a direct effect on mental health problems, as well as an indirect effect through stigma, using 5,000 bootstrap samples. The direct paths from motor PD symptoms to stigma (b = .352, p < .001) and from stigma to mental health problems (b = .106, p = .006) were both statistically significant. Further, the direct path from motor PD symptoms to mental health problems was statistically significant in the model (b = .232, p < .001).

Next it was examined whether the mediational effect from motor PD symptoms through stigma to mental health problems differed as a function of participants' level of social support. The overall model predicting mental health problems was significant, $F(5, 386) = 41.276$, p < .001, R^2 = .348. Table 6 presents the b-weights, standard errors, p-values, and 95% bias-correct bootstrap confidence intervals for each of the paths included in the moderated-mediation model. The motor PD symptoms x social support interaction with stigma as the criterion variable was not significant (b = -.001, p = .978). When mental health problems were the criterion, the interactions between motor PD symptoms x social support (b = .088, p = .003; Figure 3) and stigma x social support (b = -.081, p = .002; Figure 4) were significant. A regression was run to examine a potential effect of multicollinearity (due to two interaction terms being used in the same PROCESS model) on the direction of the motor PD symptoms x social support moderation, as the effect of high social support is not in the expected direction. While the overall model was

significant $F(3, 388) = 56.511$, $p < .001$, $R^2 = .304$, the interaction was not ($\beta = .073$, $p = .161$).

This suggests that the direction may be an artifact of multicollinearity in the model.

Table 6. *Model Summary for the Association between Motor PD Symptoms and Mental Health Problems through Stigma by Social Support (N = 392).*

Social Support	Estimate (SE)	95% Bias-corrected bootstrap confidence interval
Model 1: DV = Stigma		
Motor Symptoms	.35(.05)***	.26 to .44
Social Support	-.29(.05)***	-.40 to -.19
Motor Symptoms × Social Support	-.001(.03)	-.07 to .07
R^2	.30***	
Model 2: DV = Mental Health		
Motor Symptoms	.23 (.04)***	.16 to .30
Stigma	.11(.04)**	.03 to .18
Social Support	-.18(.04)***	-.26 to -.10
Motor Symptoms × Social Support	.09(.03)**	.03 to .15
Stigma × Social Support	-.08(.03)**	-.13 to -.03
R^2	.35***	

Note. 5,000 bootstrap samples. DV = dependent variable. **$p < .05$. ***$p < .001$.

Figure 3

Moderation of motor PD symptoms to mental health by levels of social support found to be an artifact of multicollinearity

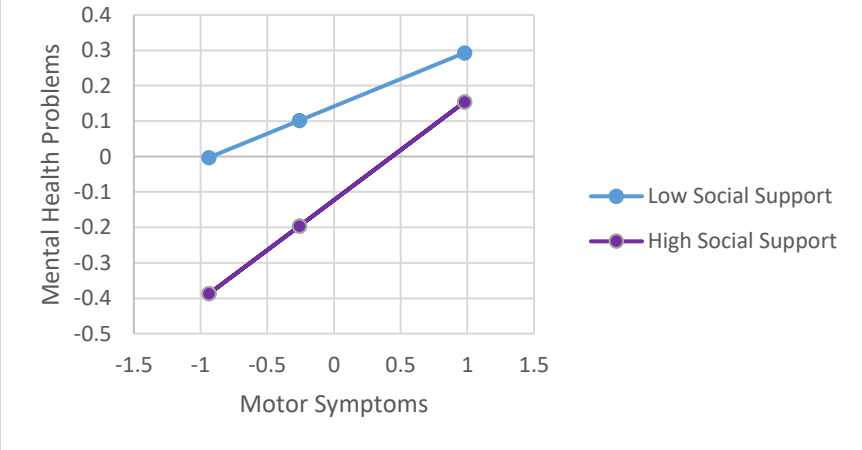
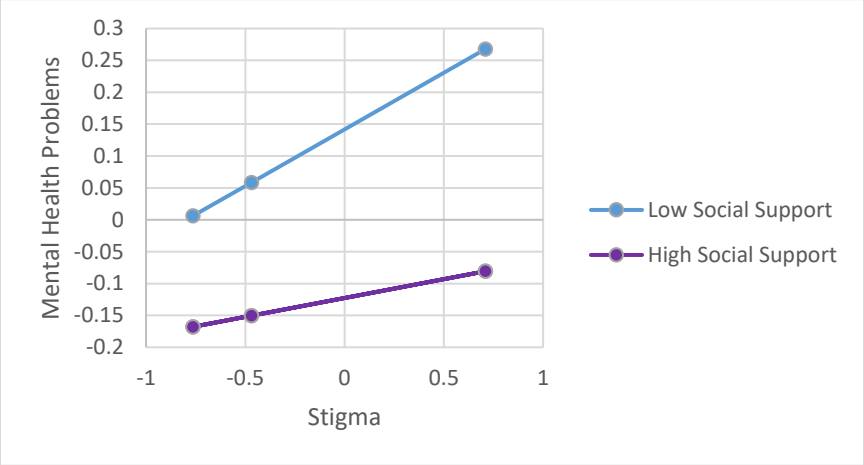


Figure 4

Moderation of stigma to mental health by levels of social support



Follow-up analyses examined the conditional effects at different levels of the moderator (social support). There were conditional direct and indirect effects of motor PD symptoms on mental health problems by social support. Specifically, motor PD symptoms had a larger direct effect on mental health problems for participants with high social support relative to those with low social support, suggesting an accelerating effect of social support on this direct effect inconsistent with H4 but reflective of error and an artifact of multicollinearity devoid of meaning (Table 7). Conversely, the indirect effect of motor PD symptoms on mental health problems through stigma was stronger at lower levels of social support than at high levels, suggesting that this mediational model held only for those with low social support and therefore a buffering effect consistent with H4 and supporting a moderated mediation (Table 8).

Table 7. *Conditional Direct Effects of Motor PD Symptoms on Mental Health Problems at Levels of Social Support* (*N* = 392)

Social Support	Effect	Estimate (SE)	95% Bias-corrected bootstrap confidence interval
Low	.15*	.04	.07 to .24
High	.28*	.04	.20 to .37

Note. *Effects are considered statistically significant if the p value is < .05 and the 95% bias-corrected bootstrap confidence interval does not encapsulate zero.

Table 8. *Conditional Indirect Effects of Motor PD Symptoms on Mental Health Problems at Levels of Social Support* (*N* = 392)

Social Support	Effect	Estimate (SE)	95% Bias-corrected bootstrap confidence interval
Low	.06*	.02	.02 to .11
High	.02	.02	-.02 to .06

Note. *Effects are considered statistically significant if the 95% bias-corrected bootstrap confidence interval does not encapsulate zero.

Moderated mediation: Non-motor symptoms as predictor and social support as moderator. In the second moderated mediation (Model 59), non-motor PD symptoms was specified to have a direct effect on mental health problems, as well as an indirect effect through stigma, using 5,000 bootstrap samples. The direct paths from non-motor PD symptoms to stigma (b = .229, p < .001) and from stigma to mental health problems (b = .130, p < .001) were both statistically significant. Further, the direct path from non-motor PD symptoms to mental health problems was statistically significant in the model (b = .341, p < .001).

Next, it was examined whether the mediational effect from non-motor PD symptoms through stigma to mental health differed as a function of participants' level of social support. The overall model predicting mental health was significant, $F(5, 386) = 55.182$, $p < .001$, $R^2 = .417$. Table 9 presents the *b*-weights, standard errors, *p*-values, and 95% bias-correct bootstrap confidence intervals for each of the paths included in the moderated-mediation model. The non-motor PD symptoms x social support interaction with stigma as the criterion variable was not

significant (b = -.023, p = .501). When mental health was the criterion, the interaction between non-motor PD symptoms x social support was not significant (b = .037, p = .146), while stigma x social support was significant (b = -.050, p = .031; Figure 5).

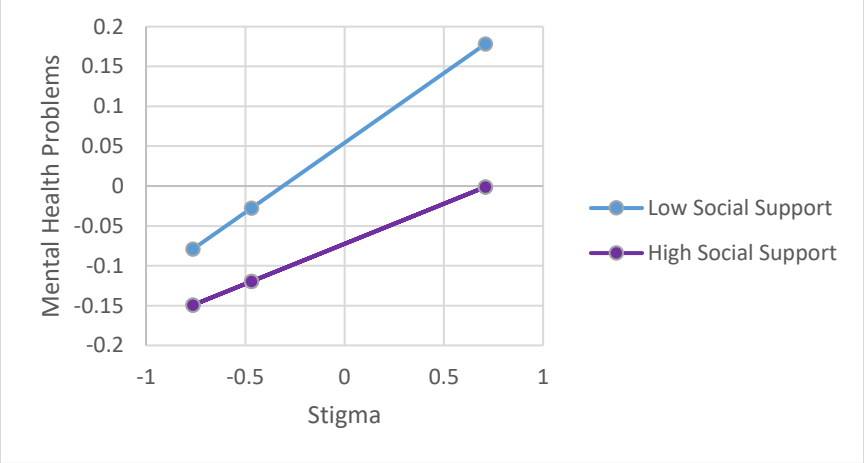
Table 9. *Model Summary for the Association between Non-Motor Symptoms and Mental Health through Stigma by Social Support (N = 392).*

Social Support	Estimate (SE)	95% Bias-corrected bootstrap confidence interval
Model 1: DV = Stigma		
Non-Motor Symptoms	.23(.05)***	.13 to .33
Social Support	-.30(.06)***	-.42 to -.18
Non-Motor Symptoms × Social Support	-.02(.03)	-.09 to .04
R^2	.24***	
Model 2: DV = Mental Health		
Non-Motor Symptoms	.34(.04)***	.27 to .41
Stigma	.13(.03)***	.06 to .20
Social Support	-.09(.04)*	-.17 to -.004
Non-Motor Symptoms × Social Support	.04(.03)	-.01 to .09
Stigma × Social Support	-.05(.02)*	-.10 to -.005
R^2	.42***	

Note. 5,000 bootstrap samples. DV = dependent variable. **p < .05. ***p < .001.

Figure 5

Moderation of stigma to mental health by levels of social support



Follow-up analyses examined the indirect effect at different levels of the moderator (social support; Table 10). While the indirect effect did not change by vacillating between

statistical significance and non-significance, the size of the indirect effect did decrease in the hypothesized direction (H4).

Table 10. *Conditional Indirect Effects of Non-Motor PD Symptoms on Mental Health at Levels of Social Support* (*N* = 392)

Social Support	Effect	Estimate (SE)	95% Bias-corrected bootstrap confidence interval
Low	.04*	.02	.01 to .09
High	.02*	.01	.001 to .05

Note. *Effects are considered statistically significant if the 95% bias-corrected bootstrap confidence interval does not encapsulate zero.

Moderated mediation: Motor symptoms as predictor and spirituality as moderator. In the third moderated mediation model, motor PD symptoms was specified to have a direct effect on mental health, as well as an indirect effect through stigma, using 5,000 bootstrap samples. The direct paths from motor PD symptoms to stigma (b = .427, p < .001) and from stigma to mental health (b = .161, p < .001) were both statistically significant. Further, the direct path from motor PD symptoms to mental health was statistically significant in the model (b = .187, p < .001).

Next, it was examined whether the mediational effect from motor PD symptoms through stigma to mental health problems differed as a function of participants' level of spirituality. The overall model predicting mental health was significant, $F(5, 343) = 55.367$, p < .001, R^2 = .447. Table 11 presents the b-weights, standard errors, p-values, and 95% bias-correct bootstrap confidence intervals for each of the paths included in the moderated-mediation model. The motor PD symptoms x spirituality interaction with stigma as the criterion variable was not significant (b = -.08, p = .053). When mental health was the criterion, both the interactions between motor PD symptoms x spirituality (b = .08, p = .019; Figure 6) and stigma x spirituality were significant (b = -.07, p = .017; Figure 7). A regression was run to examine a potential effect of

multicollinearity on the direction of the motor PD symptoms x spirituality moderation, as the effect of high spirituality was not in the expected direction. While the overall model was significant $F(3, 345) = 75.290$, $p < .001$, $R^2 = .396$, the interaction was not ($\beta = .037$, $p = .402$). This suggests again that the direction of the interaction is an artifact of multicollinearity in the model devoid of meaning.

Table 11. *Model Summary for the Association between Motor Symptoms and Mental Health through Stigma by Spirituality (N = 349).*

Spirituality	Estimate (SE)	95% Bias-corrected bootstrap confidence interval
Model 1: DV = Stigma		
Motor Symptoms	.43(.05)***	.34 to .52
Spirituality	-.12(.05)**	-.21 to -.02
Motor Symptoms × Spirituality	-.08(.04)	-.17 to .001
R^2	.27***	
Model 2: DV = Mental Health		
Motor Symptoms	.19(.03)***	.12 to .04
Stigma	.16(.04)***	.09 to .23
Spirituality	-.29(.03)***	-.36 to -.23
Motor Symptoms × Spirituality	.08(.03)**	.01 to .14
Stigma × Spirituality	-.07(.03)**	-.12 to -.01
R^2	.45***	

Note. 5,000 bootstrap samples. DV = dependent variable. **$p < .05$. ***$p < .001$.

Figure 6

Moderation of motor PD symptoms to mental health by levels of spirituality found to be an artifact of multicollinearity

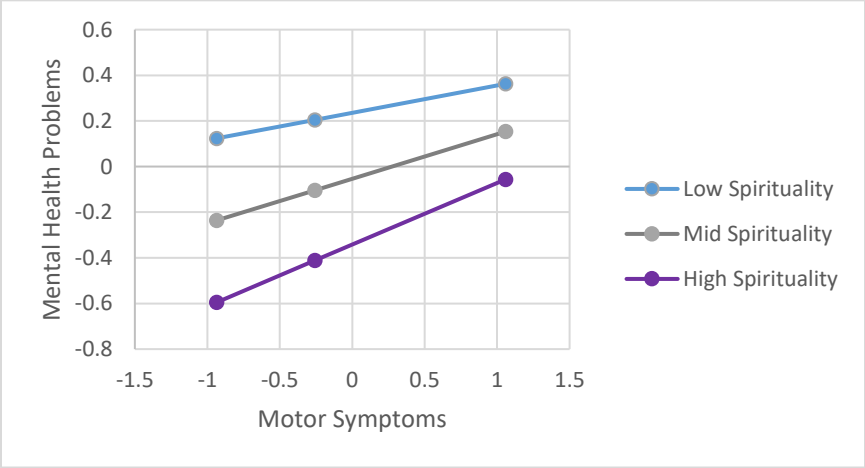
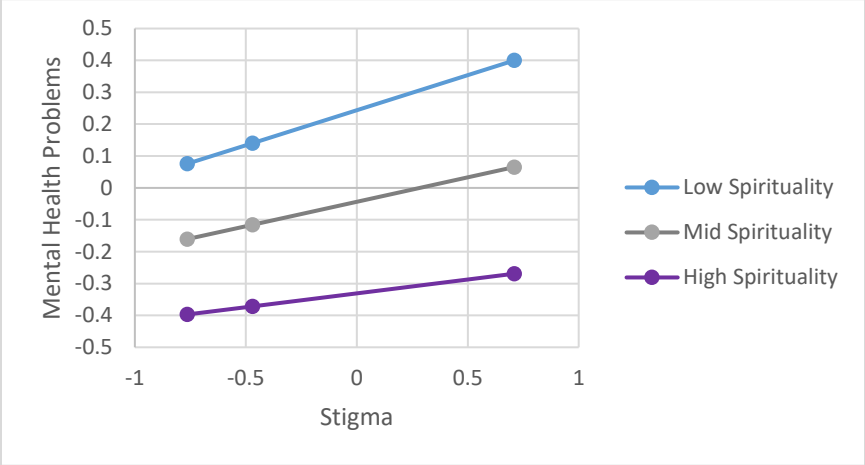


Figure 7

Moderation of stigma to mental health by levels of spirituality



Follow-up analyses examined the conditional effects at different levels of the moderator (spirituality). There were conditional direct and indirect effects of motor PD symptoms on mental health by spirituality. Specifically, motor PD symptoms had a larger direct effect on mental health problems for participants with high spirituality relative to those with low or mid spirituality, suggesting an intensifying effect of spirituality on this direct effect inconsistent with H5 but reflective of error and an artifact of multicollinearity devoid of meaning (Table 12). Conversely, the indirect effect of motor PD symptoms on mental health problems through stigma was stronger at lower levels of spirituality than at high levels, suggesting that this mediational model only held for those with low and mid spirituality and therefore a buffering effect consistent with H5 and supporting a moderated mediation (Table 13).

Table 12. *Conditional Direct Effects of Motor PD Symptoms on Mental Health at Levels of Spirituality* (*N* = 349)

Spirituality	Effect	Estimate (SE)	95% Bias-corrected bootstrap confidence interval
Low	.12*	.04	.04 to .20
Mid	.20*	.03	.13 to .26
High	.27*	.05	.17 to .37

Note. *Effects are considered statistically significant if the p value is < .05 and the 95% bias-corrected bootstrap confidence interval does not encapsulate zero.

Table 13. *Conditional Indirect Effects of Motor PD Symptoms on Mental Health at Levels of Spirituality* (*N* = 349)

Spirituality	Effect	Estimate (SE)	95% Bias-corrected bootstrap confidence interval
Low	.11*	.03	.04 to .18
Mid	.06*	.03	.02 to .12
High	.03	.03	-.02 to .10

Note. *Effects are considered statistically significant if the 95% bias-corrected bootstrap confidence interval does not encapsulate zero.

Moderated mediation: Non-motor symptoms as predictor and spirituality as moderator. In the fourth moderated mediation model, non-motor PD symptoms was specified to have a direct effect on mental health, as well as an indirect effect through stigma, using 5,000 bootstrap samples. The direct paths from non-motor PD symptoms to stigma (b = .343, p < .001) and from stigma to mental health (b = .151, p < .001) were both statistically significant. Further, the direct path from non-motor PD symptoms to mental health was statistically significant in the model (b = .281, p < .001).

Next, it was examined whether the mediational effect from non-motor PD symptoms through stigma to mental health differed as a function of participants' level of spirituality. The overall model predicting mental health was significant, $F(5, 343) = 70.002$, $p < .001$, $R^2 = .505$. Table 14 presents the *b*-weights, standard errors, *p*-values, and 95% bias-correct bootstrap confidence intervals for each of the paths included in the moderated-mediation model. The non-

motor PD symptoms x spirituality interaction with stigma as the criterion variable was not significant (b = -.052, p = .174). When mental health was the criterion, the interaction between non-motor PD symptoms x spirituality (b = -.002, p = .940) and stigma x spirituality were also not significant (b = -.025, p = .346). These results indicate no pattern of interactions with spirituality. Two regressions were run to examine a potential effect of multicollinearity (due to two interaction terms being used in the same PROCESS model) on the interaction of nonmotor PD symptoms x spirituality and stigma x spirituality. For nonmotor PD symptoms x spirituality, the overall model was significant $F(3, 345) = 30.098$, $p < .001$, $R^2 = .464$; however, the interaction was not (β = -.039, p = .355). The same was true for stigma x spirituality, with the overall model being significant $F(3, 345) = 25.168$, $p < .001$, $R^2 = .392$, while the interaction was not (β = -.055, p = .225). This supports the findings of the PROCESS model and suggests this was not a result of multicollinearity in the model.

Table 14. *Model Summary for the Association between Non-Motor Symptoms and Mental Health through Stigma by Spirituality (N = 349).*

Spirituality	Estimate (SE)	95% Bias-corrected bootstrap confidence interval
Model 1: DV = Stigma		
Non-Motor Symptoms	.34(.05)***	.24 to .44
Spirituality	-.12(.05)**	-.23 to -.02
Non-Motor Symptoms × Spirituality	-.05(.04)	-.13 to .02
R^2	.44***	
Model 2: DV = Mental Health		
Non-Motor Symptoms	.28(.03)***	.22 to .34
Stigma	.15(.03)***	.09 to .21
Spirituality	-.24(.03)***	-.30 to -.18
Non-Motor Symptoms × Spirituality	-.002(.03)	-.05 to .05
Stigma × Spirituality	-.03(.03)	-.08 to .03
R^2	.51***	

Note. 5,000 bootstrap samples. DV = dependent variable. **p < .05. ***p < .001.

Follow-up analyses examined the indirect effect at different levels of the moderator (spirituality; Table 15). The indirect effect of non-motor PD symptoms on mental health

problems through stigma was stronger at low and mid-levels of spiritualty than at high levels, suggesting that this mediational model held only for those with low and mid-spirituality and therefore a buffering effect consistent with H5.

Table 15. *Conditional Indirect Effects of Non-Motor PD Symptoms on Mental Health at Levels of Spirituality* (*N* = 349)

Spirituality	Effect	Estimate (SE)	95% Bias-corrected bootstrap confidence interval
Low	.07*	.03	.02 to .12
Mid	.05*	.02	.01 to .10
High	.04	.03	-.003 to .10

Note. *Effects are considered statistically significant if the 95% bias-corrected bootstrap confidence interval does not encapsulate zero.

Regressions. In order to identify the patterns of connections among PD symptoms, stigma, and mental health, a series of hierarchical multiple regressions were performed using SPSS Software Package, Version 26. In the first hierarchical multiple regression, age was entered in the first step, motor and non-motor symptoms in the second, and stigma as the outcome. The overall model was significant and explained 34.4% of variance in stigma [$F(3, 388) = 67.77$, $p < .001$, $\Delta R^2 = .344$]. When considering each symptom type separately, only the motor symptoms uniquely predicted stigma ($\beta = .450$, $p < .001$), while non-motor ($\beta = .102$, $p = .055$) did not. Age was also a unique predictor ($\beta = -.318$, $p < .001$) of stigma.

In the second hierarchical multiple regression, age and education were entered in the first step, motor and non-motor symptoms in the second, with apathy as the outcome. The overall model was significant and explained 11.1% of variance in apathy [$F(4, 386) = 12.01$, $p < .001$, $\Delta R^2 = .111$]. When considering each symptom type separately, both the motor symptoms ($\beta = .176$, $p = .005$) and non-motor ($\beta = .153$, $p = .014$) uniquely predicted apathy. Age ($\beta = .063$, $p = .201$) and years of education ($\beta = -.093$, $p = .059$) were not unique predicators of apathy.

In the third hierarchical multiple regression, age and education were entered in the first step, motor and non-motor symptoms in the second, with stigma as the outcome. The overall model was significant and explained 33.2% of variance in stigma [$F(4, 386) = 47.92$, $p < .001$, $\Delta R^2 = .332$]. When considering each symptom type separately, only the non-motor symptoms uniquely predicted anxiety (β =.477, $p < .001$), while motor (β =.095, $p = .082$) did not. Age was also a unique predictor (β = -.123, $p = .004$) of anxiety, while years of education (β = -.070, $p = .102$) was not.

In the fourth hierarchical multiple regression, age and education were entered in the first step, motor and non-motor symptoms in the second, with depression as the outcome. The overall model was significant and explained 38.3% of variance in stigma [$F(4, 386) = 59.96$, $p < .001$, $\Delta R^2 = .383$]. When considering each symptom type separately, both the motor symptoms (β =.152, $p = .004$) and non-motor (β =.465, $p < .001$) uniquely predicted depression. Age (β = -.134, $p = .001$) and years of education (β = -.108, $p = .008$) were also was also unique predictors of depression.

Discussion

As incidence of PD rises, so too does the need to examine the social consequences of PD. Such consequences include increased experiences of stigma as a results of symptoms of PD (Moore & Knowles, 2006). Individuals with PD who experience higher rates of stigma may isolate and withdraw themselves as a result of negative and stigmatizing experiences (Burgener & Berger, 2008), which may ultimately lead to poorer mental health outcomes (Hatzenbuehler et al., 2013; Mak et al., 2007; Meyer, 2003; Pascoe & Smart Richman, 2009). Relatively little research exists examining the potential mediation effect of stigma on the relationship between symptoms and poor mental health or on the role of social support and spirituality as potential

protective factors. This study sought to examine the connections among PD symptoms (motor and non-motor), stigma, and mental health problems, as well as examine whether social support and spirituality moderated these relationships.

Descriptives

Symptoms. In the current study, participants reported an average of nine motor symptoms and nine non-motor symptoms. These motor and non-motor symptom averages were composed of items from both the PDQ-39 and NMS, and therefore the rates cannot be compared directly to other studies. However, the rate of non-motor symptoms was very similar to the overall average reported by Martinez-Martin and colleagues (2007) of 10.25 non-motor symptoms (SD = 5.3; range 0-28), with a range by country from a low of 9.28 (SD = 4.3) in Italy and high of 12.71 (SD = 5.7) in Israel (Martinez-Martin et al., 2007) of the six countries included in the study. To the author's knowledge, no similar assessment exists for motor symptoms.

Apathy. In the current study, 37.2% of the sample reported significant levels of apathy. This rate is comparable with previous research which suggests apathy occurs for approximately 40% of individuals with PD (Brok et al., 2015) as well as in 20-36% of newly diagnosed individuals (Pagonabarraga et al., 2015). As data were collected during participants' first neuropsychological evaluation, this comparison makes sense. It is, however, unknown whether this first assessment was a patient's first time being seen at the clinic having had a previous diagnosis or if they were newly diagnosed patients. This distinction may be important as levels of apathy vary across the disease course (Dujardin et al., 2007; Pluck & Brown, 2002; Wee et al., 2016).

Anxiety. In the current study, of those who completed the BAI, 56.1% had at least mild anxiety. Of those who completed the GAD-7, 34.8% had at least mild anxiety. While the GAD-7

rates are in line with previous research, the BAI figures greatly exceeded the estimated rates of 25% to 40% of individuals with PD who will experience clinically significant anxiety (Kano et al., 2011; Pontone et al., 2009; Quelhas & Costa, 2009; Starkstein, Robinson, Leiguarda, & Preziosi, 1993; Walsh & Bennett, 2001). There are several possible reasons for the differences in the performance of the BAI and GAD-7. These include the number of individuals administered each measure (BAI N = 274; GAD-7 N = 158). Other reasons why the BAI may indicate higher levels of anxiety include that anxiety is part of prodromal syndrome of PD (Chen et al., 2015; Jacob et al., 2010) and many individuals may experience anxiety related to specific PD symptoms (Coakeley et al., 2014; Dissanayaka et al., 2016; Martens et al., 2016). These may be better captured by the items of the BAI than the GAD-7.

Depression. In the current study, of those who completed the BDI-II, 24% of individuals had at least mild depression. Of those who completed the PHQ-9, 51% had at least mild depression. Of those who completed the GDS-SF, 38.5% had at least mild depression, with no participants scoring in the severe depression range. It is noteworthy that the GDS-SF did not record severe depression compared to the BDI-II or the PHQ-9. There are several possible explanations for this. The first is that the constructs being measured by the GDS-SF, BDI-II and PHQ-9 may be slightly different. However, in a study comparing nine different depression scales in PD patients, it was suggested that all nine performed equally well with the exception of the Unified Parkinson's Disease Rating Scale for Depression (Williams et al., 2012). Furthermore, the GDS-SF was only administered to those age 65 and above, so it may be that there may be something significant about older PD patients or unique about this group of older PD patients. Overall, those administered the PHQ-9 reported the highest levels of depression, followed by the BDI-II, and the GDS-SF. The rates of depression indicated by the BDI-II were only slightly

higher than other studies, while the PHQ-9 was significantly higher (Quelhas & Costa, 2009). This again may be a result of differences in the measures or in the patients who were administered the measures. There is also significantly more data from the BDI-II (N = 287) than either the PHQ-9 (N = 155) or GDS-SF (N = 70), which may also account for some of the differences. A possible explanation for why participants in the current study had higher self-reported rates of depression than previous studies is that the majority of the sample was male. These individuals are potentially experiencing significant life changes, both due to age and gender. For example, they may have been forced to recently retired, facing a different type of retirement than previously envisioned, or facing an early retirement due to changing abilities. This disruption caused by PD symptoms may pose a greater threat to a masculine self-identity and contribute to depression (Oliffe et al., 2013; Reitzes et al., 1996; Solimeo, 2008).

Stigma. In the current study, participants reported an average of 16.20 (SD=21.20, range 0-100). This was lower than in other studies which means ranged from 34.67 to 48.13 (Jenkinson et al., 1995; Martinez-Martin et al., 2007; Peto et al., 2001). There are many possible reasons for this including this was a clinical sample from a specialized multidisciplinary PD clinic. Having access to the clinic and these resources may suggest a less stigmatizing environment and therefore the individuals feel and internalize less stigma (Ma et al., 2016). These individuals may also have greater support in managing their PD identities, which may protect them from feeling as stigmatized by it (Roger & Medved, 2010). Finally, these questions were asked within the context of a clinical interview, so the individuals with PD had a relationship with a provider, which may influence the responses they provide compared to other research methods, such as a mailed survey (Peto et al., 1998).

Social Support. In the current study, participants reported an average score of 90.10 (SD=17.03, range 8.33-100). This was notably higher than in other studies which means ranged from 24.25 to 48.99 (Jenkinson et al., 1995; Martinez-Martin et al., 2007; Peto et al., 2001). There are many possible explanations for this, including that this is a clinical sample which likely requires support/caregivers (Martínez-Martín et al., 2007). Prior relationships may be being redefined as individuals take on informal caregiving roles (Jeyathevan et al., 2019; Roberto et al., 2019). By adding a caregiving role on top of an existing relationship, this may increase the perception of social support in the context of the existing relationship. Furthermore, the questions assessing social support focused on relationship problems and lack of support from spouses, close relationships, family, and friends. Informal caregivers most often fall into one of these categories. As such, informal caregiving may be enmeshed with other social relationships in these responses, producing this high rate.

Spirituality. In the current study, participants reported an average spirituality score of 7.77 (SD=2.02, range 0-10). Compared to a group of hospitalized depressed older adults responding to the same item (M = 6.57, SD = 2.61 at baseline; M = 7.86, SD = 1.76 at discharge), the spirituality scores were on par (Piderman et al., 2011). This may be in part because spirituality has been demonstrated to increase in older adulthood (MacKinlay, 2016) and has been shown to be a common form of coping in clinical populations (Prizer et al., 2019; Roger & Hatala, 2018).

Correlations. The results of the bivariate correlations mostly followed expected patterns. Specifically, motor and non-motor symptoms were highly correlated. Further, for both symptom types, as one experienced increasing numbers of symptoms one also experienced higher levels of stigma and mental health issues. This may be because as individuals have increasing symptoms,

they may experience greater difficulty caring for themselves and have higher levels of disability (Ellis et al., 2016; Rana et al., 2017). In the extant literature, both difficulty caring for oneself and greater disability may contribute to both higher rates of mental health issues and higher levels of stigma (Ma et al., 2016; Maffoni et al., 2017; Thangavelu et al., 2020). For stigma, as with previous literature, it was correlated with lower social support (Birtel et al., 2017; Ma et al., 2016) and more mental health problems (Hatzenbuehler et al., 2013; Mak et al., 2007; Meyer, 2003; Pascoe & Smart Richman, 2009).

Social support and spirituality were each related to decreased mental health problems, which supports previous literature (Harris et al., 2010; Reynolds, 2017; Simpson et al., 2006; Takahashi et al., 2016). Among the demographics, age was associated with greater symptoms and more social support (Petrou, Dwamena, Foerster, MacEachern, Bohnen, Muller, et al., 2015; Shulman et al., 2016). While stereotypes suggest that older adults experience less social support (Makita et al., 2019), the evidence is mixed regarding social support and aging (Cattan et al., 2005; Dai et al., 2016; Weiner et al., 2016). However, because of informal caregiving needs of this clinical PD population, this effect may be mitigated.

Education, sex, and age correlated with many of the study variables. Education was associated with lower mental health problems which supports previous studies (Alegría et al., 2000; Steele et al., 2007; Wang et al., 2000). Slight sex differences existed in the current study such that females reported more non-motor symptoms. In previous studies, women have reported greater symptoms for both physical (Lichtman et al., 2018; Styrke et al., 2013) and mental health conditions (Newmann, 1984; Norris et al., 2001). While there may be sex differences in the presentation of conditions, there are also gender-role differences in reporting and seeking help for health conditions (Gast & Peak, 2011; Wyke et al., 1998). Contrary to previous studies

(Antonucci & Akiyama, 1987; Caetano et al., 2013; White et al., 2009), males in the current study reported significantly higher levels of social support. However, in a previous study with a clinical population, males also reported higher social support (Berard et al., 2012). This suggests populations with chronic or major health conditions may perceive or experience social support differently. Additionally, in the current study, there was a greater proportion of males in the study sample. Another possible explanation is that the onset of PD in men is approximately 2-2.1 years earlier than women (Gillies et al., 2014; Miller & Cronin-Golomb, 2010), which may lead to needing caretaking sooner or more time for adaptation of one's social network. No sex differences existed in mental health problems in the current study, which is not supported in the literature (Clancy & Gove, 1974; de Sá Junior et al., 2019) which may in part be due to the fact that over half the sample was male. Interestingly, spirituality was not related to age, sex, or education. Previous studies have found that older adults (MacKinlay, 2016) and women (Francis & Wilcox, 1996; Kregting et al., 2019; Maselko & Kubzansky, 2006) are more likely to report spirituality. Regarding education, individuals with less formal education are more likely to identify as religious or religious and spiritual, with those with more formal education outpacing other groups as identifying themselves as "spiritual, but not religious" (Lipka & Gecewicz, 2017). The distinction between spirituality and religiosity may have important clinical implications in the future.

Mediational Analyses: Motor and Non-Motor Symptoms

Stigma partially mediated the relationship between both motor and non-motor symptoms and mental health problems. These findings are consistent with prior research that suggests that motor symptoms (Hermanns, 2013; Lyons et al., 1997; Maffoni et al., 2017) and non-motor symptoms (Hemmesch et al., 2009; Jaywant & Pell, 2010; Tickle-Degnen et al., 2011) are

related to stigma, and that stigma is related to mental health problems (Hatzenbuehler et al., 2013; Mak et al., 2007; Meyer, 2003; Pascoe & Smart Richman, 2009). However, to the author's knowledge, there are no other studies which have tested these relationships in a mediation.

Moderated Mediations

Social support as a moderator of motor symptoms, stigma, and mental health.

Consistent with the study hypotheses, the present study documented a moderating effect of social support on the relationships among motor symptoms, stigma, and mental health problems. The indirect effect of motor PD symptoms on mental health problems through stigma was stronger at lower levels of social support than at high levels, suggesting that this mediational model held only for those with low social support and therefore a buffering effect. This is possibly because individuals who have high support are shielded or better able to cope with stigma (Cadden et al., 2018; Kondrat et al., 2018). Many individuals experience stigma as a threat, attack, or dismissal of an identity (Herek et al., 20090126; Howarth, 2006). Having someone—a friend, a family member, a significant other/partner, etc.—to talk and get advice from may allow an individual to process the situation and increase perceptions of available coping resources (Stevens et al., 2013). Specifically, social support provides individuals with an outlet to gain support, insight, and ideas about stigmatizing encounters and to brainstorm new, effective ways of confronting stigma (Chronister et al., 2013; Dudley, 2000). These findings are also supported theoretically by the minority stress model (Meyer, 2003), which posits that distal minority stressors (e.g., stigma) are associated with increased mental health problems. Additionally, the impact of distal stressors on mental health may be mitigated by protective factors such as social support.

Social support as a moderator of non-motor symptoms, stigma, and mental health.

Consistent with the study hypotheses, there was an indirect effect in the present study which decreased in the hypothesized direction. However, the effect did not change between significant and non-significant to suggest an overall moderating effect of social support on the relationships among non-motor symptoms, stigma, and mental health problems. Furthermore, there was an interaction of stigma x social support onto mental health problems, such that the buffering effect was stronger for those at low levels of social support than high. Overall, those at high levels of social support reported lower levels of mental health problems compared to those with low social support. These findings are consistent with the pattern found for motor symptoms and suggest that whether the experience of PD stigma is being driven by motor or non-motor PD symptoms, social support is a potentially important protective factor.

Spirituality as a moderator of motor symptoms, stigma, and mental health.

Consistent with the study hypotheses, the present study documented a moderating effect of spirituality on the relationships among motor symptoms, stigma, and mental health problems. The indirect effect of motor PD symptoms on mental health problems through stigma was stronger at lower levels of spirituality than at high levels, suggesting that this mediational model only held for those with low and mid spirituality and therefore a buffering effect. A possible explanation for this may be that aspects of spirituality are related to meaning making and purpose (Doolittle & Farrell, 2004). As individuals experience increasing symptoms, it may force them to confront the purpose or meaning of their illness and potentially reexamine fundamental beliefs about themselves and the world (Egnew, 2018; Helgeson & Zajdel, 2017; Shaw et al., 2005; Zeligman et al., 2018). With such a broad range of possible options imbedded in the single spirituality question used in the present study, individuals could easily have

interpreted this question to be consistent with their own form of spiritual coping (e.g., prayer, meditation, healing circles, etc.; Klaassen et al., 2006; Narayanasamy, 2002; Siegel & Schrimshaw, 2002).

There was also a significant interaction of stigma x spirituality predicting mental health, such that increased spirituality reduced (buffered) the effect of stigma on mental health. Reasons for this may include that at low and mid-levels of spirituality, as stigma increases, individuals may be more prone to tap into the shame and blame narrative of chronic illness/disability (i.e., that their chronic illness/disability is a punishment or result of sin, or that they are being tested) rather than finding meaning through benevolent reframing (i.e., karma or the will of God) and to utilize support from a spiritual/religious community or leader (Clarke & Cardman, 2002; Johnstone et al., 2007; Treloar, 2002). Gall and colleagues (2005) propose a theoretical framework of spiritual coping. In this transactional model, individuals must appraise and eventually make meaning out of a stressor, which ultimately influences their well-being (i.e., emotional, social, physical, and spiritual). This appraisal and meaning making process is influenced by person factors, spiritual connections, and spiritual coping behaviors. Individuals low in spirituality, but with greater stigma may be making greater personal attributions related to their diagnosis, feel greater hopelessness about their situation, or have fewer spiritual coping behaviors (Gall et al., 2005). These findings are also supported theoretically by the minority stress model (Meyer, 2003), in which distal minority stressors (e.g., stigma) are associated with increased mental health problems. Furthermore, the impact of distal stressors on mental health may be buffered by protective factors such as spirituality.

Spirituality as a moderator of non-motor symptoms, stigma, and mental health. Consistent with the study hypotheses, there was a moderating effect of spirituality on the

relationships among non-motor symptoms, stigma, and mental health problems. Specifically, the indirect effect of non-motor PD symptoms on mental health problems through stigma was stronger at low and mid-levels of spiritualty than at high levels, suggesting that this mediational model held only for those with low and mid-spirituality. The non-motor PD symptom findings are consistent with the pattern found for motor symptoms and similarly suggest that whether the experience of PD stigma is being driven by motor or non-motor PD symptoms, spirituality is a potentially important protective factor.

While there was a moderating effect, there were no significant interactions such that any of the individual paths were moderated by spirituality. One possible explanation for this is that a single-item spirituality measure was used. With a single item it is not possible to measure internal reliability. Further a single item generally has lower sensitivity and specificity, suggesting a greater chance for error within this single-item measure. Finally, there is a question of validity; whether a single item can capture the construct. The spirituality item used was rather broad (i.e., regarding meaning/purpose, a higher power, etc.), which may have diffused the meaning. However, as motor symptoms did have significant interactions and follow-up regressions were also not significant, it is possible that for these individuals with PD an interaction effect of spirituality is not present. This may suggest more potential benefits for target intervention with individuals with certain motor PD symptoms—as opposed to non-motor PD symptoms—particularly in regard to stigma.

Regressions. A series of multiple hierarchal regressions showed that age and motor symptoms uniquely predicted stigma, motor and non-motor symptoms predicted apathy, non-motor symptoms and age predicted anxiety, and motor symptoms, non-motor symptoms, age, and education predicted depression. Age and motor symptoms predicting stigma supports prior

research which suggests that it is the visible symptoms of PD that are most highly stigmatized (Hermanns, 2013; Lyons et al., 1997; Maffoni et al., 2017). Age may be operating in a two-fold manner in that these individuals are experiencing ageism and are more progressed in their disease, thus likely to have more motor (visible) symptoms (Petrou, Dwamena, Foerster, MacEachern, Bohnen, Muller, et al., 2015; Shulman et al., 2016).

For apathy, being predicted by both motor and non-motor symptoms may be the result of the fact that goal directed, motivated behavior is more challenging in the face of greater symptoms (Linde et al., 2017; Massimo et al., 2018). As it becomes increasingly difficult to accomplish tasks, one may find it is harder to find the desire or motivation to do so. Regarding depression, this finding supports previous literature that has clearly established a link between age, education, and symptoms to depression (Brody et al., 2018; Katon & Ciechanowski, 2002; Mirowsky & Ross, 1992; Palinkas et al., 1990). However, this study does so specifically within the context of individuals with PD.

In the current study, non-motor symptoms and anxiety were related, although, anxiety is often categorized as a non-motor symptom (Durcan et al., 2019; Pfeiffer, 2016). For the purpose of this study, non-motor symptoms included things such as “Unexpectedly fallen asleep during the day,” “Loss or change in your ability to taste or smell,” “Unexplained pain (not due to known conditions such as arthritis” or “Seeing or hearing things that you know or are told are not there.” For many, this loss of control (i.e., falling asleep, seeing/hearing things, and unexplained pain) may be very unsettling and anxiety provoking. Further, symptoms of PD are not always constant over time, and so individuals may be concerned about when and how bad a symptom experience will be (Zhu et al., 2017).

Potential Implications

The findings from the current study, guided by the minority stress model, provide insight into the way PD symptoms are related to stigma and how that in turn influences mental health outcomes. Furthermore, social support and spirituality may act as protective factors to mitigate the relationships among PD symptoms, stigma, and mental health. From the current study, there is a possibility to inform future targets for clinical interventions.

For example, as age and motor symptoms were found to uniquely predict stigma, this may help to identify individuals with PD who may be at greater risk for stigmatization based upon their clinical presentation and therefore may require targeted intervention. Additionally, as stigma was found to mediate the relationship between both motor and non-motor PD symptoms and mental health, health professionals working with individuals with PD may wish to consider stigma and discrimination in how they present and design treatment options for PD patients. One example of this may include connecting individuals with PD to support groups or mental health services to process experiences of PD-related stigma.

There have been very few studies which have examined psychosocial treatments for apathy, anxiety, and depression among individuals with PD. Acute management of anxiety and depression using cognitive-behavioral therapy and other therapy modalities among individuals with PD have demonstrated promise, although the long-term effects of these approaches have had variable results (Yang et al., 2012). This may require further research to find the best evidence-based practice to help facilitate disability identities and increase utilization of these processes.

From these results, it will also be important to consider the role of social support, as it was found to weaken the relationships among PD symptoms, stigma, and mental health. This

suggests it may be important to find ways to increase and foster social support among individuals with PD. In the current study, males reported higher levels of social support, which suggests it may be of particular importance for clinicians working with female patients (and potentially gender minority patients) to ensure they have access to a strong social support network. Social support may come from a variety of places, including informal caregivers. However, for individuals with PD, it may be important to have and maintain a number of positive close relationships (Simpson et al., 2006). Additionally, considering both the type of support individuals with PD receive (e.g., instrumental, emotional, and/or informational) and from whom the support is received (e.g., family, friends, work colleagues, or health care professionals) is vital, as this can have an influence on desired outcomes (Ravenek & Schneider, 2009).

Spirituality was also found, in the current study, to weaken the relationships among PD symptoms, stigma, and mental health. Spiritual practices may buffer stress from chronic health problems and increase quality of life (Delgado, 2007). Spirituality has also been demonstrated to be a strong source of support for many individuals with chronic health problems (McNulty et al., 2004; Narayanasamy, 2002). Including an assessment of spiritual practice and beliefs into patient assessments may help health care providers better understand an individual with PD's worldview, and subsequently view of chronic illness, if there is a spiritual community of support, and if spiritual interventions and coping mechanisms may be appropriate and helpful for the individual (Nichols & Hunt, 2011).

Limitations and Future Directions

The current findings and potential implications should be viewed within the context of the following limitations. First, this study was a secondary data analysis of PD patients from a multidisciplinary PD clinic at a public, academic medical center in the Mid-Atlantic region. The

sample was majority White, male, and had at least some college education. This sample may not be generalizable, given the access to the specialty clinic and demographics. Also, as the multidisciplinary PD clinic was located in a large urban center, this sample may not be representative of individuals in more rural areas or those with more limited access to care. Future studies may wish to collect data from a wider range of movement disorder clinics in both urban and rural areas to have a more representative sample.

Second, the data were cross-sectional. As a result, causality cannot be established regarding the time-ordered effect of greater PD symptoms leading to increased stigma and then to more mental health problems. For example, in the PDQ-39 (which was used for motor PD symptoms, non-motor PD symptoms, social support, and stigma) participants are asked to rate how often something has occurred over the previous month (Peto et al., 1998). From this it would not be possible to establish whether an experience of stigma occurred before or after the presentation of a PD symptom. Future studies may wish to employ a longitudinal study design to establish temporal order among the variables.

Third, there were several challenges in measurement that resulted from this secondary data analysis. As it was a secondary dataset, no additional items or measures could be included. In the current study, no spirituality demographic information was obtained. Future studies may wish to survey individuals about their spiritual/religious affiliation to see if there are differences across spiritual/religious orientations. There were also multiple measures for the same construct (i.e., depression and anxiety). These measures were scored separately according to scoring instructions, converted into z-scores, and then averaged. The motor and non-motor symptom measures were composed of items from both the PDQ-39 and NMS—both self-report measures—which were coded at the item level as either motor or non-motor using current PD

criteria of motor and non-motor symptoms and clinician review. There was only a single-item spirituality wellness measure. With only a single item, it is not possible to measure internal reliability, there is lower sensitivity and specificity, and the validity of a single item is questionable. Finally, the conceptualization and operationalization of stigma and social support on the PDQ-39 is limiting. For stigma, the questions were more inwardly focused (i.e., "Felt you had to conceal your Parkinson's from people," "Avoided situations which involve eating or drinking in public," or "Felt worried by other people's reaction to you"). The social support items were negatively valanced (i.e., "had problems" or "lacked support"), broad/vague (i.e., "support" and "problems"), and focused on a limited range of relationships (i.e., "close personal relationships," "spouse or partner," or "family or close friends"). To address some of measurement limitations of the present study, future studies may wish to use a physician symptom rating scale such as The Movement Disorder Society-Sponsored Revision of the Unified Parkinson's Disease Rating Scale or the Hoehn and Yahr scale, a single mental health measure for each construct, and additional spirituality, stigma, and social support measures.

Conclusions

The current study is among very few studies to examine the relationships among PD symptoms (motor and non-motor), stigma, and mental health problems among individuals with PD. Furthermore, it tested a mediational model linking these constructs among a clinical sample of PD patients. The present study also examined a potential moderating effect of social support and religiosity on the relationships among PD symptoms (motor and non-motor), stigma, and mental health problems for individuals with PD.

For individuals with PD, social support buffered the relationships between motor symptoms and mental health problems and stigma and mental health problems (in both models).

Spirituality buffered the relationships between motor symptoms and mental health problems and stigma and mental health problems (for motor symptoms only). Findings from this study suggest that clinical intervention research with this population should focus on increasing social support—with attention paid to sex differences—and opportunities for spiritual engagement where appropriate. Furthermore, psychosocial treatments for apathy, anxiety, and depression among individuals with PD should be examined to find the best evidence-based practices to help facilitate disability identities and increase utilization of these processes. The current findings suggest that social support and spirituality could potentially buffer mental health problems for individuals with PD.

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Appendix A

Parkinson's Disease Questionnaires-39 (PDQ-39)

Due to having Parkinson's disease, how often have you experienced the following, during the last month?

		Never	Occasionally	Sometimes	Often	Always
		0	1	2	3	4
M	1. Had difficulty doing the leisure activities you would like to do?	0	1	2	3	4
M	2. Had difficulty looking after your home, for example, housework, cooking or yardwork?	0	1	2	3	4
M	3. Had difficulty carrying grocery bags?	0	1	2	3	4
M	4. Had problems walking half a mile?	0	1	2	3	4
M	5. Had problems walking 100 yards (approximately 1 block)?	0	1	2	3	4
M	6. Had problems getting around the house as easily as you would like?	0	1	2	3	4
M	7. Had difficulty getting around in public places?	0	1	2	3	4
M	8. Needed someone else to accompany you when you went out?	0	1	2	3	4
E	9. Felt frightened or worried about falling in public?	0	1	2	3	4
M	10. Been confined to the house more than you would like?	0	1	2	3	4
M	11. Had difficulty showering and bathing?	0	1	2	3	4
M	12. Had difficulty dressing?	0	1	2	3	4
M	13. Had difficulty with buttons or shoelaces?	0	1	2	3	4
M	14. Had problems writing clearly?	0	1	2	3	4
M	15. Had difficulty cutting up your food?	0	1	2	3	4
M	16. Had difficulty holding a drink without spilling it?	0	1	2	3	4
E	17. Felt depressed?	0	1	2	3	4
E	18. Felt isolated and lonely?	0	1	2	3	4
E	19. Felt weepy or tearful?	0	1	2	3	4
E	20. Felt angry or bitter?	0	1	2	3	4
E	21. Felt anxious?	0	1	2	3	4
E	22. Felt worried about your future?	0	1	2	3	4

ST	23. Felt you had to hide your Parkinson's from people?	0	1	2	3	4
ST	24. Avoided situations which involve eating or drinking in public?	0	1	2	3	4
ST	25. Felt embarrassed in public?	0	1	2	3	4
ST	26. Felt worried about other people's reaction to you?	0	1	2	3	4
Ss	27. Had problems with your close personal relationships?	0	1	2	3	4
Ss	28. Lacked the support you needed from your spouse or partner?	0	1	2	3	4
Ss	29. Lacked the support you needed from your family or close friends?	0	1	2	3	4
N	30. Unexpectedly fallen asleep during the day?	0	1	2	3	4
E	31. Had problems with your concentration, for example when reading or watching TV?	0	1	2	3	4
E	32. Felt your memory was failing?	0	1	2	3	4
E	33. Had distressing dreams or hallucinations?	0	1	2	3	4
M	34. Had difficulty speaking?	0	1	2	3	4
N	35. Felt unable to communicate effectively?	0	1	2	3	4
E	36. Felt ignored by people?	0	1	2	3	4
N	37. Had painful muscle cramps or spasms?	0	1	2	3	4
N	38. Had aches and pains in your joints or body?	0	1	2	3	4
E	39. Felt uncomfortably hot or cold?	0	1	2	3	4

Note: M = motor PD symptom; N = non-motor PD symptom; E = excluded; ST = Stigma Subscale; Ss = Social Support subscale

Appendix B

Non-Motor Symptoms Questionnaire (NMS)

The movement symptoms of Parkinson's are well known. However, other problems can sometimes occur as part of the condition or its treatment. It is important that the doctor knows about these, particularly if they are troublesome for you.

A range of problems is listed below. Please tick the box 'Yes' if you have experienced it during the past month. The doctor or nurse may ask you some questions to help decide. If you have not experienced the problem in the past month tick the 'No' box. You should answer 'No' even if you have had the problem in the past but not in the past month.

Have you experienced any of the following in the last month?

		Yes	No
M	1. Dribbling of saliva during the daytime	Yes	No
N	2. Loss or change in your ability to taste or smell	Yes	No
M	3. Difficulty swallowing food or drink or problems with choking	Yes	No
N	4. Vomiting or feelings of sickness (nausea)	Yes	No
N	5. Constipation (less than three bowel movements a week) or having to strain to pass stool (feces)	Yes	No
N	6. Bowel (fecal) incontinence	Yes	No
N	7. Feeling that your bowel emptying is incomplete after having been to the toilet	Yes	No
N	8. A sense of urgency to pass urine makes you rush to the toilet	Yes	No
N	9. Getting up regularly at night to pass urine	Yes	No
N	10. Unexplained pains (not due to known conditions such as arthritis)	Yes	No
N	11. Unexplained change in weight (not due to change in diet)	Yes	No
N	12. Problems remembering things that have happened recently or forgetting to do things.	Yes	No
E	13. Loss of interest in what is happening around you or doing things	Yes	No

N	14. Seeing or hearing things that you know or are told are not there	Yes	No
N	15. Difficulty concentrating or staying focused.	Yes	No
E	16. Feeling sad, "low" or "blue"	Yes	No
E	17. Feeling anxious, frightened, or panicky	Yes	No
E	18. Feeling less interested in sex or more interested in sex	Yes	No
E	19. Finding it difficult to have sex when you try	Yes	No
N	20. Feeling lightheaded, dizzy or weak standing from sitting or lying	Yes	No
M	21. Falling	Yes	No
N	22. Finding it difficult to stay awake during activities such as working, driving or eating	Yes	No
N	23. Difficulty getting to sleep at night or staying asleep at night	Yes	No
N	24. Intense, vivid dreams or frightening dreams	Yes	No
N	25. Talking or moving about in your sleep as if you are "acting" out a dream	Yes	No
N	26. Unpleasant sensations in your legs at night or while resting, and a feeling that you need to move	Yes	No
N	27. Swelling of your legs	Yes	No
N	28. Excessive sweating	Yes	No
N	29. Double vision	Yes	No
N	30. Believing things are happening to you that other people say are not true	Yes	No

Note: M = motor PD symptom; N = non-motor PD symptom; E = excluded

Appendix C

Apathy Scale (AS)

For each question, please place a mark in the response that best describes you.

	Not at all 0	Slightly 1	Some 2	A lot 3
1. Are you interested in learning new things?	0	1	2	3
2. Does anything interest you? ***(Excluded)***	0	1	2	3
3. Are you concerned about your condition?	0	1	2	3
4. Do you put much effort into things?	0	1	2	3
5. Are you always looking for something to do?	0	1	2	3
6. Do you have plans and goals for the future?	0	1	2	3
7. Do you have motivation?	0	1	2	3
8. Do you have the energy for daily activities? ***(Excluded)***	0	1	2	3
9. Does someone have to tell you what to do each day?	0	1	2	3
10. Are you indifferent to things?	0	1	2	3
11. Are you unconcerned with many things?	0	1	2	3
12. Do you need a push to get started on things?	0	1	2	3
13. Are you neither happy nor sad, just in between?	0	1	2	3
14. Would you consider yourself apathetic?	0	1	2	3

Appendix D

Generalized Anxiety Disorder-7 (GAD-7)

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

	Not at all 0	Several days 1	More than half the days 2	Nearly every day 3
1. Feeling nervous, anxious, or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it's hard to sit still	0	1	2	3
6. Being easily annoyed or irritable	0	1	2	3
7. Being afraid as if something awful might happen	0	1	2	3

If you checked off any problem on this questionnaire so far, 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?

Not Difficult At All	Somewhat Difficult	Very Difficult	Extremely Difficult
0	1	2	3

Appendix E

Beck Anxiety Inventory (BAI)

Below is a list of common symptoms of anxiety. Please carefully read each item in the list. Indicate how much you have been bothered by that symptom during the past month, including today, by circling the number in the corresponding space in the column next to each symptom.

	Not at all 0	Mildly, but it didn't bother me much 1	Moderately - it wasn't pleasant at times 2	Severely - it bothered me a lot 3
1. Numbness or tingling	0	1	2	3
2. Feeling hot ***(Excluded)***	0	1	2	3
3. Wobbliness in legs ***(Excluded)***	0	1	2	3
4. Unable to relax	0	1	2	3
5. Fear of worst happening	0	1	2	3
6. Dizzy or lightheaded ***(Excluded)***	0	1	2	3
7. Heart pounding/racing	0	1	2	3
8. Unsteady ***(Excluded)***	0	1	2	3
9. Terrified or afraid	0	1	2	3
10. Nervous	0	1	2	3
11. Feeling of choking ***(Excluded)***	0	1	2	3
12. Hands trembling ***(Excluded)***	0	1	2	3
13. Shaky/unsteady ***(Excluded)***	0	1	2	3
14. Fear of losing control	0	1	2	3
15. Difficulty in breathing	0	1	2	3
16. Fear of dying	0	1	2	3
17. Scared	0	1	2	3
18. Indigestion	0	1	2	3
19. Faint/lightheaded ***(Excluded)***	0	1	2	3
20. Face flushed	0	1	2	3
21. Hot/cold sweats ***(Excluded)***	0	1	2	3

Appendix F

Beck Depression Inventory (BDI)

Below is a list of common symptoms of depression. Please carefully read each item in the list. Indicate how much you have been bothered by that symptom during the past month, including today, by circling the number in the corresponding space in the column next to each symptom.

	0	1	2	3
1. Sadness	0. I do not feel sad.	1. I feel sad much of the time.	2. I am sad all the time.	3. I am so sad or unhappy that I can't stand it.
2. Pessimism	0. I am not discouraged about my future.	1. I feel more discouraged about my future than I used to be.	2. I do not expect things to work out for me.	3. I feel my future is hopeless and will only get worse.
3. Past Failure	0. I do not feel like a failure.	1. I have failed more than I should have.	2. As I look back, I see a lot of failures.	3. I feel I am a total failure as a person.
4. Loss of Pleasure	0. I get as much pleasure as I ever did from the things I enjoy.	1. I don't enjoy things as much as I used to.	2. I get very little pleasure from the things I used to enjoy.	3. I can't get any pleasure from the things I used to enjoy.
5. Guilty Feelings	0. I don't feel particularly guilty.	1. I feel guilty over many things I have done or should have done.	2. I feel quite guilty most of the time.	3. I feel guilty all of the time.
6. Punishment Feelings	0. I don't feel I am being punished.	1. I feel I may be punished.	2. I expect to be punished.	3. I feel I am being punished.
7. Self-Dislike	0. I feel the same about myself as ever.	1. I have lost confidence in myself.	2. I am disappointed in myself.	3. I dislike myself.
8. Self-Criticalness	0. I don't criticize or blame myself more than usual.	1. I am more critical of myself than I used to be.	2. I criticize myself for all of my faults.	3. I blame myself for everything bad that happens.
9. Suicidal Thoughts or Wishes	0. I don't have any thoughts of killing myself.	1. I have thoughts of killing myself, but I would not carry them out.	2. I would like to kill myself.	3. I would kill myself if I had the chance.
10. Crying	0. I don't cry any more than I used to.	1. I cry more than I used to.	2. I cry over every little thing.	3. I feel like crying, but I can't.

11. Agitation	0. I am no more restless or wound up than usual.	1. I feel more restless or wound up than usual.	2. I am so restless or agitated that it's hard to stay still.	3. I am so restless or agitated that I have to keep moving or doing something.
12. Loss of Interest	0. I have not lost interest in other people or activities.	1. I am less interested in other people or things than before.	2. I have lost more of my interest in other people or things.	3. It's hard to get interested in anything.
13. Indecisiveness	0. I make decisions about as well as ever.	1. I find it more difficult to make decisions than usual.	2. I have much greater difficulty in making decisions than I used to.	3. I have trouble making any decisions.
14. Worthlessness	0. I do not feel I am worthless.	1. I don't consider myself as worthwhile and useful as I used to.	2. I feel more worthless as compared to other people.	3. I feel utterly worthless.
15. Loss of Energy	0. I have as much energy as ever.	1. I have less energy than I used to have.	2. I don't have enough energy to do very much.	3. I don't have enough energy to do anything.
16. Changes in Sleeping Pattern ***(Excluded)***	0. I have not experienced any change in my sleeping pattern.	1. I sleep somewhat more than usual OR I sleep somewhat less than usual.	2. I sleep a lot more than usual OR I sleep a lot less than usual.	3. I sleep most of the day OR I wake up 1-2 hours early and can't get back to sleep.

Changes in Sleeping Pattern: Select the specific option that applies to you in Item 16. ***(Excluded)***	0. I have not experienced any change in my sleeping pattern.	1. I sleep somewhat more than usual.	2. I sleep somewhat less than usual.	3. I sleep a lot more than usual.	4. I sleep a lot less than usual.	5. I sleep most of the day.	6. I wake up 1-2 hours early and can't get back to sleep.

17. Irritability	0. I am no more irritable than usual.	1. I am more irritable than usual.	2. I am much more irritable than usual.	3. I am irritable all the time.
18. Changes in Appetite	0. I have not experienced any change in my appetite.	1. My appetite is somewhat less than usual OR My appetite is somewhat greater than usual.	2. My appetite is much less than before OR My appetite is much greater than usual.	3. I have no appetite at all OR I crave food all the time.

Changes in appetite: Select the specific option that	0. I have not experienced	1. My appetite is somewhat	2. My appetite is somewhat	3. My appetite is much less	4. My appetite is much	5. I have no	6. I crave food all the time.

applies to you in Item 18.	any change in my appetite.	less than usual.	greater than usual.	than before.	greater than usual.	appetite at all.	

19. Concentration Difficulty ***(Excluded)***	0. I can concentrate as well as ever.	1. I can't concentrate as well as usual.	2. It's hard to keep my mind on anything for very long.	3. I find I can't concentrate on anything.
20. Tiredness or Fatigue	0. I am no more tired or fatigued than usual.	1. I get more tired or fatigued more easily than usual.	2. I am too tired or fatigued to do a lot of the things I used to do.	3. I am too tired or fatigued to do most of the things I used to do.
21. Loss of Interest in Sex ***(Excluded)***	0. I have not noticed any recent change in my interest in sex.	1. I am less interested in sex than I used to be.	2. I am much less interested in sex now.	3. I have lost interest in sex completely.

Appendix G

Patient Health Questionnare-9 (PHQ-9)

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

	Not at all 0	Several days 1	More than half the days 2	Nearly every day 3
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling asleep, staying asleep, or sleeping too much ***(Excluded)***	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself, feeling that you are a failure, or feeling that you have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things such as reading the newspaper or watching television ***(Excluded)***	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thinking that you would be better off dead or that you want to hurt yourself in some way	0	1	2	3

If you checked off any problem on this questionnaire so far, 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?

Not Difficult At All	Somewhat Difficult	Very Difficult	Extremely Difficult
0	1	2	3

Appendix H

Geriatric Depression Scale Short Form (GDS-SF)

Choose the best answer for how you have felt over the past week:

	Yes 0	No 1
1. Are you basically satisfied with your life?	0	1
2. Have you dropped many of your activities and interests?	0	1
3. Do you feel that your life is empty?	0	1
4. Do you often get bored?	0	1
5. Are you in good spirits most of the time?	0	1
6. Are you afraid that something bad is going to happen to you	0	1
7. Do you feel happy most of the time?	0	1
8. Do you often feel helpless?	0	1
9. Do you prefer to stay at home, rather than going out and doing new things?	0	1
10. Do you feel you have more problems with memory than most? ***(Excluded)***	0	1
11. Do you think it is wonderful to be alive now?	0	1
12. Do you feel pretty worthless the way you are now?	0	1
13. Do you feel full of energy?	0	1
14. Do you feel that your situation is hopeless?	0	1
15. Do you think that most people are better off than you are?	0	1

Appendix I

Linear Analogue Self-Assessment (LASA)

Directions: Please circle the number (0-10) best reflecting your response to the following that best describes your feelings during the past week, including today.

	As bad as it can be 1	2	3	4	5	6	7	8	9	As good as it can be 10
1. How would you rate your physical well-being over the past week? This question refers to such things as fatigue, activity, etc.	1	2	3	4	5	6	7	8	9	10
2. How would you rate your emotional well-being over the past week? This question refers to such things as depression, anxiety, stress, etc.	1	2	3	4	5	6	7	8	9	10
3. How would you rate your spiritual well-being over the past week? This question refers to such things as a sense of meaning and purpose, relationship with God, etc.	1	2	3	4	5	6	7	8	9	10
4. How would you rate your intellectual well-being over the past week? This question refers to such things as the ability to think clearly, to concentrate, to remember, etc.	1	2	3	4	5	6	7	8	9	10
5. How would you rate your overall well-being over the past week?	1	2	3	4	5	6	7	8	9	10

Note: Bolded item (item number three) is single-item used from this scale.

Vita

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