Resilience in Parkinson’s disease: An empirical examination of age-related components of the construct

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RESILIENCE IN PARKINSON’S DISEASE: AN EMPIRICAL EXAMINATION OF AGE-RELATED COMPONENTS OF THE CONSTRUCT

By Andrea M. Garroway, M.S.

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

Virginia Commonwealth University, 2014

Major Director: Bruce D. Rybarczyk, Ph.D.
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Richmond, Virginia
May 2014
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Goal-flexibility

Optimism

Moderating effect of age

Illness uncertainty and spirituality

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RESILIENCE IN PARKINSON’S DISEASE: AN EMPIRICAL EXAMINATION OF AGE-RELATED COMPONENTS OF THE CONSTRUCT

By Andrea M. Garroway, M.S.

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

Virginia Commonwealth University, 2014

Major Director: Bruce D. Rybarczyk, Ph.D., Major Professor, Department of Psychology

Although Parkinson’s disease (PD) is commonly characterized by motor symptoms and physical limitations, there is growing recognition of nonmotor and mood symptoms associated with the disease as well. There has been limited research exploring how individual coping might affect the relationships between PD symptoms and mental health outcomes. The resilience construct was originally developed within the child literature, and it is often used in conceptualizing how people have adaptive or positive outcomes when facing adversity. Current resilience measures may not adequately assess the construct within an older population, however, given the unique emotion regulation and coping skills seen in late life.

This survey study of 139 community-dwelling adults with PD (M age = 64.25 years, SD = 10.12, range 34-89 years) investigated whether resilience moderated the relationship between PD-related factors (nonmotor symptoms, functional impairment, and disease symptom-related QOL) and mental health outcomes (depression, apathy, satisfaction with and adjustment-quality
Further analyses explored whether hypothesized age-related resilience components (optimism, goal-flexibility, and meaning-making ability), accounted for unique variance above and beyond a standard resilience measure (Resilience Scale for Adults).

Results indicated that disease symptom-related QOL predicted depression and adjustment-related QOL, while functional impairment predicted apathy, life satisfaction, and adjustment related QOL. Participants overall reported moderate to high resilience; resilience was a significant predictor of all mental health/QOL outcome measures, and those with comparatively lower self-reported resilience had worse disease symptoms. Resilience did not moderate the relationship between disease symptoms and mental health/QOL. Meaning-making ability and goal-flexibility accounted for unique variance above and beyond the standard resilience measure for several outcome variables. Age was a significant moderator, such that the protective value of meaning-making ability and optimism on depression were greater for younger compared to older participants.

This study highlighted the presence of moderate to high resilience in PD patients, however those with comparatively lower resilience had poorer outcomes. Other coping variables appear to be important contributors to mental health/QOL beyond a standard resilience measure. Patient age also affected several outcomes, emphasizing the importance of further integration of developmental literature into our understanding of resilience in chronic disease management.
Resilience in Parkinson’s disease: An empirical examination of age-related components of the construct

Parkinson’s disease (PD) is a common neurodegenerative disorder, second only to Alzheimer’s disease. PD onset typically occurs in middle-aged and older populations, however people as young as 30 years old can be diagnosed with the disease. PD prevalence rates are 0.5% to 1% among older adults between ages 65 and 69, with increasing rates of 1% to 3% among those 80 years or older (Nussbaum & Ellis, 2003). The exact cause of PD is unknown, although researchers generally believe that genetic factors, environmental triggers, and neurological indicators, such as Lewy bodies, are potential causes of PD. The four cardinal features of PD are resting tremor, rigidity, postural instability, and bradykinesia, or the slowness of movement (Jankovic, 2008; Pandya, Kubu, & Giroux, 2008; Robottom et al., 2012). PD can also involve sensory symptoms, such as impaired sense of smell, and autonomic symptoms, including gastrointestinal, urinary, and sexual dysfunction (Pandya et al., 2008).

PD is complex and often affects both physical and cognitive functioning, however the disease course, severity, and symptom presentation can vary widely across patients. Some people can become severely disabled and require complete assistance from a caregiver or another provider, while others experience only minor motor difficulties. In contrast to other neurodegenerative diseases, such as Alzheimer’s disease, patients with PD may or may not experience dementia. Various reviews have estimated that approximately 24% to 31% of PD patients have dementia (Aarsland, Zaccai, & Brayne, 2005; Anderson, 2004; Pandya et al., 2008), with dementia and cognitive dysfunction becoming more common in the later stages of the disease.
Although PD is often characterized by motor symptoms, it is also associated with mental health and mood problems. Researchers hypothesize that mood changes are due to both the distress caused by impairment and actual chemical changes in the brain from the disease itself (Cummings, 1992). The most common mood disorder associated with PD is depression, with hypothesized neuronal loss in various subcortical nuclei resulting in serotonin, norepinephrine, and dopamine depletion. Depressive symptoms in PD often present differently than in people with idiopathic depression. For example, PD patients report dysphoria, pessimism, irritability, sadness, and suicidal ideation, but little guilt, blame, or feelings of punishment (Cummings, 1992; Cummings & Masterman, 1999). Prevalence rates of depression are generally between 40%-45% (Cummings, 1992; Lemke, 2008), however the rates can range depending on the diagnostic criterion used. One review found that 17% of PD patients met criteria for major depressive disorder, 22% met criteria for minor depression, 13% met criteria for dysthymia, while 35% of patients exhibited some form of clinically significant depression (Reijnders, Ehrt, Weber, Aarsland, & Leentjens, 2008). The prevalence of depression in PD is comparable to depression rates seen in similar neurological disorders, such as approximately 40% in AD (Holtzer et al., 2005), 41% in MS (Rickards, 2005), and slightly higher prevalence rates compared to post-stroke patients that range between 10% and 34% (Rickards, 2005).

Apathy is another common psychological symptom in PD that is distinct from depression, but nonetheless detrimental for quality of life (QOL) (Oguru, Tachibana, Toda, Okuda, & Oka, 2010). PD patients with depression also have higher rates of anxiety symptoms (Lemke, 2008), which often coincide with wearing-off or on-off fluctuations associated with medication dosing (Pandya et al., 2008). Despite their high prevalence, psychiatric symptoms in
PD are often under-diagnosed, with one study finding that treating neurologists failed to identify depression and anxiety over half of the time (Shulman, Taback, Rabinstein, & Weiner, 2002).

Typical first-line treatment for PD involves dopamine substitution using levodopa (L-DOPA) or dopamine agonists, which help improve muscle movement and delay severe disability. Depressive symptoms are often treated with antidepressant medications, including TCAs, and even some dopamine agonists are effective in reducing depression in PD (Andersen, Aabro, Gulmann, Hjelmsted, & Pedersen, 1980; Rektorova et al., 2003). Since PD is a degenerative disease, however, and no known neuroprotective or regenerative treatments exist, it is imperative for researchers to study methods for minimizing disease impact and maintaining good QOL.

A complementary and growing area of study is resilience, which has gained interest within geropsychology in recent years. The resilience construct has been used to explain findings of older patients demonstrating generally positive outcomes in terms of QOL and mental health despite disease and illness (Bombardier, Ehde, Stoelb, & Molton, 2010; Zautra & Reich, 2011). There have been some investigations of resilience in later life within a developmental context (e.g., selective optimization and compensation [Baltes & Baltes, 1990], advanced emotion regulation due to age [Ong, Bergman, & Boker, 2009]), however there have been other suggestions for studying late life resilience as its own construct (Smith & Hayslip, 2012).

The current study proposes to delineate the resilience construct within an older disease population by studying the relationship between PD nonmotor symptoms (NMS) and impairment, individual psychological factors, and mental health outcomes. More specifically, the project will explore how resilience and related components are related to depression, apathy, and QOL within an older PD population. Given the high rates of depression and apathy in PD
patients, as well as the powerful role of NMS and mental health on overall functioning (Arun, Bharath, Kumar Pal, & Singh, 2011; Weintraub, Moberg, Duda, Katz, & Stern, 2004), it is important to gain a better understanding of the psychological factors that can mitigate the negative effects of PD. By learning more about PD patients’ mental health, as well as individual characteristics that affect mental health, clinicians may ultimately be able to identify higher-risk patients and match appropriate treatments to promote better outcomes.

Review of the Literature

Parkinson’s disease and related factors. Although PD is typically characterized and often first identified by motor symptoms, a large body of research has examined the role of mental health and NMS in PD patients. One early study characterized PD patients as part of a “premature social aging” process because compared to healthy elderly controls, PD patients had little interest in social engagement and spent a large amount of time doing solitary activities (Singer, 1973). Although this term is somewhat misleading and reinforces the stereotype that aging equates withdrawal and disinterest in engagement, this idea sparked interest in investigating the psychosocial elements of PD. In line with this approach, more research has identified NMS in PD patients as an important domain to study, distinct from the cardinal physical features of PD (Pandya et al., 2008). NMS have gained attention as a major cause of disability in PD, and these symptoms can include neuropsychiatric (depression, apathy, anxiety), autonomic (bladder disturbances, sexual dysfunction), and gastrointestinal symptoms (dribbling of saliva, nausea) (Chaudhuri et al., 2006).

One important confound to recognize is that neuropsychiatric symptoms are often considered part of the NMS profile in PD patients. Within these neuropsychiatric symptoms, research generally characterizes depression as the most common psychiatric disorder associated
with PD. Apathy and QOL are also frequently studied as indicators of patients’ mental health and subjective experiences with PD. Anxiety disorders are also relatively common in PD patients. One study found that 67% of PD patients with depression had comorbid anxiety, while 92% of PD patients with anxiety had comorbid depression (Menza, Robertson-Hoffman, & Bonapace, 1993). The anxiety and depression measures were highly correlated \((r = 0.74, p < 0.001)\), with 44% of the variance in anxiety scores explained by depression scores. While both depression and anxiety are presumed to be associated with underlying neurochemical changes from the PD itself, anxiety disorders in PD are not well-characterized and often include symptoms that do not meet standard diagnostic criteria (e.g., episodic anxiety associated with fluctuations in motor symptoms) (Pontone et al., 2009). Continued research is necessary to better understand anxiety symptoms in PD patients as they relate to depression and on-off medication periods, therefore the present study will limit its scope to explore depression, apathy, and QOL in PD patients. Additionally, the current project will not focus on the effects of motor impairment and physical manifestations of PD on mental health, although these factors are related to the psychological outcomes of depression, apathy, and QOL (Cummings, 1992; Schrag, Jahanshahi, & Quinn, 2000). The present study will instead focus on the relationship between other disease-related factors, specifically NMS and functional impairment, and psychological outcomes, as well as individual patient variables that presumably affect the relationship.

**Nonmotor symptoms in Parkinson’s disease.** Nonmotor symptoms (NMS) are a historically unexplored area in PD, receiving comparatively less attention than the motor manifestations of PD (Chaudhuri et al., 2006). Nearly all patients report NMS; one study found that 98.6% of patients reported at least one NMS within the past month (Barone et al., 2009). The definition of NMS is relatively broad and includes the following categories of symptoms:
neuropsychiatric (depression, apathy, anhedonia), sleep disorders (restless legs, insomnia, vivid dreaming), autonomic (bladder disturbances, sweating, sexual dysfunction), gastrointestinal (dribbling of saliva, reflux, dysphagia/choking), sensory (pain, olfactory disturbance), and other symptoms (fatigue, blurred vision) (Chaudhuri, Yates, & Martinez-Martin, 2005). Certain NMS can generate a notable increase in healthcare costs if they result in the need for institutionalized care (e.g., falls due to orthostatic hypertension, hallucinations). A cost-analysis study in the UK found that total annual direct costs for PD patients living in full-time institutionalized care were more than four times higher than patients cared for at home (Findley et al., 2003). Despite the high prevalence and high healthcare-related costs of NMS, these symptoms are often under-recognized and under-treated, and only within the last 10 years have researchers begun developing a formal measure to assess NMS in PD (Chaudhuri et al., 2005).

The under-diagnosis and under-recognition of NMS is an important oversight to consider, given that early intervention and treatment of NMS in PD patients can have a positive impact on mental health and QOL outcomes (Charidimou, Seamons, Selai, & Schrag, 2011). Gallagher, Lees, and Schrag (2010) demonstrated that among all NMS reported by patients, cognitive and neuropsychiatric symptoms were the most commonly recognized and documented in physicians’ clinical notes (61%-82%), while potentially embarrassing or seemingly unrelated autonomic symptoms (i.e., urinary symptoms, sexual problems) were more poorly recognized (<50%). Although neuropsychiatric symptoms were the most recognized, these relatively low rates are still somewhat surprising (64% recognition for depression/anxiety) given that the evaluations were from physicians at specialty movement disorders clinics, not simply general practitioners.

Another study found similar results after assessing diagnostic accuracy from PD clinicians (Shulman et al., 2002), with treating neurologists identifying even fewer NMS than in
the Gallagher et al. (2010) study. The PD patients in the Shulman and colleagues (2002) study (n = 101) reported depression and anxiety prevalence rates comparable to other studies (44% and 39%, respectively). The treating neurologists, however, identified depression and anxiety in only 21% and 19% of their patients. Using a diagnostic accuracy calculation based on the concordance of the physician's impression with the results of the standardized rating scales, the physicians had an overall diagnostic accuracy rate of 35% for depression and 42% for anxiety. One difference between these studies is that Gallagher and colleagues (2010) used a specific NMS questionnaire (NMSQuest; Martinez-Martin et al., 2007), while Shulman et al. (2002) simply had PD patients report symptoms across a battery of standardized tests. This methodological difference is important to note, since the NMSQuest has been validated in PD patients, while only one of the assessment tools used in the Shulman et al. (2002) study has been validated with PD patients (BDI; Levin, Llabre, & Weiner, 1988). Despite these limitations in the Shulman et al. (2002) study, one can still conclude that the neurologists’ diagnostic impressions were inaccurate relative to the self-reported symptoms on standardized measures and generally lower than the known prevalence rates in PD patients.

Several studies have also explored the relationship between motor and NMS in PD patients. There is some evidence that NMS can fluctuate in response to dopaminergic treatment commonly used to manage motor symptoms, although this treatment is often not sufficient enough to effectively control the NMS (Poewe & Mahlkne, 2011). NMS are also often more disabling or subjectively troubling to patients than even the motor symptoms. One study found that the major causes of disability in PD patients were due to symptoms unimproved by L-dopa, including falls, autonomic disturbance, neuropsychiatric symptoms, and dementia (i.e., NMS).
(Hely, Morris, Reid, & Trafficante, 2005). Motor fluctuations and dyskinesia were also common, but not rated as disabling compared to the NMS.

Another study similarly addressed the frequency and disability of NMS compared to motor symptoms (Witjas et al., 2002). Witjas and colleagues asked 50 PD patients in a structured interview to rate whether or not their NMS fluctuations seemed to coincide with their motor fluctuations (e.g., “on”, “pre-on”, “off”, “pre-off” states). Patients were also asked to rate the level of disability in each fluctuation subgroup, as well as which fluctuation category was most incapacitating (motor or nonmotor). Results indicated that NMS fluctuations were generally linked with motor fluctuations, suggesting that an underlying dopaminergic deficiency may be implicated. The most commonly reported NMS included mood fluctuations, cognitive slowing, fatigue, and akathisia (restless legs), with most NMS occurring during “off” states when the levodopa wears off and causes stiffness. One notable finding from this study was that over ¼ of the patients (28%) rated their NMS as more incapacitating and disabling than their motor fluctuations. There were no demographic or other characteristic differences between the patients who rated NMS fluctuations versus motor fluctuations as most disabling. These studies underscore the need to address NMS in the conceptualization of PD and expand our research to study the range of disease factors that play a role in patients’ QOL.

**Functional impairment in Parkinson’s disease.** The previously mentioned Findley and colleagues (2003) study in the UK highlighted the potentially costly consequences of NMS and subsequent need for formal assistance. There are other “costs” due to PD, however, such as increasing dependence on others and functional impairments. A large literature on caregivers in PD demonstrates a relationship between patients’ functional state (based on activities of daily living [ADLs]) and caregivers’ psychosocial burden (Martinez-Martin et al., 2005). The present
study will not focus on caregivers’ outcomes but will explore how patients’ functional impairments relate to their own mental health/QOL outcomes. A systematic review of 61 studies found that overall PD symptoms predicted patients’ functional abilities in physical, social, and emotional domains (Den Oudsten, Van Heck, & De Vries, 2007). Another study assessed which factors contributed to poorer QOL and disability in PD patients using a range of disability measures (Muslimovic, Post, Speelman Schmand, & de Haan, 2008). Axial impairment (postural instability and gait difficulty) emerged as the best predictor of disability as measured by the Functional Independence Measure (FIM), a tool that assesses degree of functional impairment. Although elements of PD physical symptoms and subsequent disability are often a focus for health providers, it seems that functional impairment reflects a different issue for patients that may be missed by providers. One study used multiple interview formats to differentiate between patient concerns and healthcare provider concerns, and they found that when responding to open-ended questions, PD patients identified functional ability as a more pressing concern than was expressed during the structured interview questions (Schenkman, Custon, Zhu, & Whetten-Goldstein, 2002).

Another study (Shulman et al., 2008) found that functional impairments (as measured by ADLS and IADLs) were the most sensitive indicators of emerging disability on the Unified PD Rating Scale (UPDRS) (Fahn & Elton, 1987), a commonly used measure of global disease progression. Some research suggests that patients overestimate their level of functioning compared to clinician performance ratings of ADLs and IADLs (Shulman et al., 2006). This is an important consideration within the context of coping with disease, since patient expectations and subjective assessment of health are known to influence outcomes (see Mondloch, Cole, & Frank, 2001 for a review). Additionally, there is evidence that functional impairment is malleable
and can improve with multidisciplinary rehabilitation interventions (Ellis et al., 2008). Although the previous research has demonstrated that patients’ functional impairments are rated as the worst aspects of PD, they are associated with emerging disability in PD, and targeted interventions can improve functional abilities, there has been limited exploration of the role of individual coping factors in functional impairment in PD. The single study that examined resilience in PD patients found that resilience was moderately correlated with less disability on the UPDRS (Robottom et al., 2012), however there was no direct study of the relationship between functional impairment, resilience, and mental health outcomes.

**Depression in Parkinson’s disease.** Depression in PD is difficult to diagnose due to overlapping symptoms between the two disorders, including psychomotor retardation or agitation, fatigue, apathy, and loss of appetite (Lemke, 2008; Schrag, 2006). In current practice, common depression measures are used to assess depression in PD patients (e.g., the Hamilton Depression Rating Scale, the Beck Depression Inventory, the Geriatric Depression Scale), however, there have been recent proposals for a revised DSM-IV definition of depression in PD patients to address these diagnostic challenges (Marsh, McDonald, Cummings, & Ravina, 2006). Although it is plausible that depression in PD could occur solely as a secondary reaction to the motor deficits, there is no linear correlation between depressive symptoms and severity and course of PD (Cummings, 1992). This is an important distinction for diagnostic purposes because current DSM-IV criteria would exclude the diagnosis of depression in PD if symptoms were linked exclusively to a medical condition.

**Prevalence and age of onset.** The prevalence and presentation of depression in PD depend somewhat on assessment tools. One comprehensive review of 26 studies found that the mean frequency of depression was 40%, however variations in the assessment methods across
studies resulted in a range from 4% to 70% (Cummings, 1992). A more recent review of 36 studies found similar results, with 35% of PD patients exhibiting clinically significant depressive symptoms and 17% meeting criteria for major depressive disorder (Reijnders et al., 2008). These rates are comparatively higher than average prevalence rates of depression, with 9% of U.S. adults meeting criteria for current depression at any given time (CDC, 2010). In the CDC survey (2010), prevalence rates of U.S. adults followed a U-shaped curve across age-groups, such that major depression criteria were met in 2.8%, 4.6%, and 1.6% of adults in 18-24 year olds, 45-64 year olds, and ≥ 65 year olds, respectively.

Age of onset is also often examined in relation to depressive symptoms. PD typically occurs in older populations with an average age of onset around 60 years old, although “early onset” PD can occur in people younger than 40 (NINDS, 2004). Several studies and systematic reviews have found no relationship between depression, patient age, or age of onset of PD (Cummings, 1992; Gotham, Brown & Marsden, 1986). Findings are mixed, however, with some studies demonstrating that patients with early-onset PD have significantly higher rates of depression than late onset patients (Kostic et al., 1994; Starkstein, Bertheir, Bolduc, Preziosi, & Robinson, 1989). These age-related patterns of depressive symptoms are also seen in other illness contexts, such as cancer (Williamson & Schulz, 1995), pain (Gibson & Helme, 2001), and heart transplant (Shamaskin et al., 2012). Of note in PD patients, these age-related differences are nonsignificant after controlling for disease duration (Kostic et al., 1994), which suggests that depression may be more linked to length of time to adjust to the illness, rather than simply patient age at onset.

Depression rates in PD are also relatively high when compared to other medically ill patients. One study found that PD patients had significantly higher Beck Depression Inventory
(BDI) scores than age- and sex-matched disabled controls, even though the two groups exhibited comparable levels of functional disability (Ehmann, Beninger, Gawel, & Riopelle, 1990). Similar results were seen in another study that compared PD and active rheumatoid arthritis (RA) patients (Cantello, Gilli, Riccio, & Bergamasco, 1986). The PD and RA patients both had predictable “mobile” and “immobile” periods, and for both patient groups, “immobile” periods were characterized by temporary increases in disability and worsening of mood. The PD patients, however, had significantly higher BDI scores than the RA patients during both “mobile” and “immobile” periods.

In contrast, one study found similar depression rates in PD and other chronic disease populations (Gotham et al., 1986). These researchers compared three groups (PD patients, arthritis patients, and normal elderly controls) and found higher self-rated depressive symptoms between PD patients and elderly controls, however no differences in depression scores between PD and arthritis patients. The researchers suggested that the uneven sex ratio between the arthritis and PD patients (males to females; 1:2.2 versus 1:1, respectively) could explain the nonsignificant difference in depression scores, given the known correlation between female gender and depression (Bland, 1997). If one attributes the conflicting results from the Gotham et al. (1986) study to potential sample bias, the literature suggests a consistent pattern of increased depressive symptoms in PD patients compared to other medical populations confirmed in numerous studies (Cummings, 1992; Slaughter, Slaughter, Nichols, Holmes, & Martens, 2001; Warburton, 1967).

**Depression and motor impairment.** The literature regarding depressive symptoms and motor manifestations in PD is somewhat unclear, which may be due to nuanced differences in how researchers measure motor symptoms versus degree of disability. In his review, Cummings
(1992) demonstrated that a majority of studies found no association between mood and motor symptoms of PD (i.e., rigidity, bradykinesia, and tremor). Similar results were seen in Huber, Paulson, and Shuttleworth’s study (1988), which compared motor impairment, depression, and intellectual functioning in 50 PD patients. Motor impairment was measured using a clinical condition scale that accounts for purely physical manifestations of PD (H/Y scale; Hoehn, & Yahr, 1967), depression was measured using the Hamilton Depression Scale (Hamilton, 1960), and intellectual functioning was measured with the Mini-Mental State Exam (Folstein, Folstein, & McHugh, 1975). They found a significant correlation between motor and intellectual impairment, however depression was not related to either variable.

It is possible that measurement tool plays a significant role in understanding the relationship between motor symptoms and depression. Huber et al. (1988) used the Hoehn and Yahr staging scale to assess PD progression, which is a 5-stage scale that indicates level of physical disability (e.g., stage 0 = no PD symptoms, stage 1 = unilateral symptoms, stage 3 = balance impairment but physically independent, 5 = needing wheelchair or bedridden unless assisted). The Hoehn and Yahr scale (H/Y) is very commonly used with wide applicability (Hoehn & Yahr, 1967), however it is somewhat limited in its scope and does not capture all elements of PD progression, including NMS (Goetz et al., 2004). Other studies use more holistic scales, such as the Unified PD Rating Scale (UPDRS) (Fahn & Elton, 1987), and in these studies the relationship between mood and disease progression/severity is more pronounced based on UPDRS total score (Holroyd, Currie, & Wooten, 2005; Wichowicz, Slawek, Derejko, & Cubala, 2006). The UPDRS is different from the H/Y scale in that it has four sections accounting for both physical and mental components of the disease. A recent study using two sections of the UPDRS (UPDRS II = ADLs, UPDRS III = motor examination) and the H/Y scale compared
presence and severity of depression in PD patients with their degree of motor and functional disability (Piccinni et al., 2012). These researchers found that PD patients with more severe depression symptoms had higher scores on the UPDRS II and III, as well the H/Y scale.

The results from Piccinni et al. (2012) somewhat conflict with several previous studies (e.g., Cummings, 1992; Huber et al., 1988), which found that motor symptoms and mood symptoms are generally unrelated. Holroyd et al. (2005) demonstrated that some of the inconsistencies regarding depression and disease progression depend upon how the UPDRS is analyzed. In their study, depression was associated with an increased UPDRS total score, however further analysis showed that the UPDRS II subscale (ADLs) was strongly associated with depression while the UPDRS III subscale (motor examination) was not. Thus, it seems methodological differences may explain some of the discrepancies between studies. Disease progression scales that measure exclusively physical symptoms (i.e., H/Y scale, UPDRS III) may not be as strongly related to depression, while those that incorporate disease impact and could be affected by coping (i.e., UPDRS total, UPDRS II) are more related to mood symptoms.

Consistent with this hypothesis, various studies have demonstrated a relationship between depression and functional impairment in PD. This pattern fits with a coping and adjustment perspective; although depression may not be linked with motor symptoms directly, depression may be exacerbated by or contribute to how the motor symptoms affect patients’ lives. A few studies have found no correlation between depression and functional impairment (Robins, 1976; Warburton, 1967), however most research finds that mood and degree of disability are indeed related. Liu et al. (1997) found that diagnosis and severity of depression was a significant predictor of global performance in daily functional activities. Another study with similar results found that degree of depressive symptoms and cognitive impairment accounted for 37% of the
variance in disability in PD (measured by UPDRS II), but H/Y score did not contribute significantly to the model (Weintraub et al., 2004). A more recent study compared PD patients with and without major depression (matched for gender, age of onset, and disease duration) and again found that depressed PD patients had significantly higher UPDRS scores (total and subscales) than the non-depressed controls (Papapetropoulos, Ellul, Argyriou, Chroni, & Lekka, 2006). There were no significant differences, however, between the two groups on individual motor manifestations (tremor, rigidity, instability). Another longitudinal study of 132 PD patients found that the relative change in disability over a 1-year period seemed more important in terms of impact on depression than absolute change in disability (Brown, MacCarthy, Gotham, Der, & Marsden, 1988). In sum, this pattern of findings suggests that depression in PD is not simply a reaction to the physical symptoms, but there is a more complex relationship that likely involves coping with functional disability and disease severity.

Pathophysiology of depression. Although depression in PD is not exclusively a reaction to the motor manifestations of the disease, there is likely a pathophysiological component to the neurodegenerative process that contributes to depressive symptoms (Cummings, 1992; Lemke, 2008). The pathophysiology of depression in PD is quite complex, however a hypothesized explanation, in brief, is that when monoamine neurotransmitters degenerate, such as the dopaminergic neurons of the ventral tegmental area, the corresponding reward and motivational response systems are affected. Monoaminergic systems in the brain are closely involved in reward systems and play an important role in expectancy and anticipation. Therefore, diminished effectiveness of these systems (as a result of depleted dopamine, norepinephrine, and serotonin) results in decreased reward mediation, diminished desire to perform activities, lessened expectation’s from one’s activities, and lessened sense of personal control. One can
easily see the link between these neurological changes and how they might contribute to feelings of low self-esteem, helplessness, anhedonia, and other symptoms of depression.

**Depression and quality of life.** While there are still unanswered questions regarding the etiology of depression in PD patients, the literature is very clear regarding the relationship between depression and QOL in PD patients. Depression is strongly correlated with poorer QOL, however the relative impact of depression is best understood when compared to the other disease-related, demographic, and psychosocial factors relating to health-related QOL (HR-QOL) in PD patients (see Schrag, 2006 for a review). Disease duration is not strongly correlated with HR-QOL, while disease severity is only modestly correlated (Schrag et al., 2000). Disease-related factors, such as unpredictable on-off fluctuations (“off” periods occur when medications wear off in between doses, causing worsening of symptoms) (Chapuis, Ouchchane, Metz, Gerbaud, & Durif, 2004) and night-time and morning akinesia (loss of control over voluntary movements) (Kuopio, Marttila, Helenius, Toivonen, & Rinne, 2000) are also associated with poorer HR-QOL. Of course, HR-QOL is a multifaceted variable affected by numerous interacting factors that presumably correlate with each other. Schrag (2006) compared several studies that have assessed HR-QOL in PD patients, and in the studies that used appropriate multivariate analyses, depression was clearly the most frequent factor correlated with worse HR-QOL in PD patients, more so than disease duration or severity.

Depression in PD has a clearly detrimental effect on HR-QOL, perhaps more than other illnesses due to both the pathophysiological basis of depressive symptoms related to dopamine depletion in PD, along with the typical “reactive” adjustment to declines and disability. A recent hospital-based prospective study compared PD patients (n= 46) to non-PD controls (n = 30) with chronic medical conditions (Arun et al., 2011). The non-PD controls were recruited from a
general medical clinic, and their chronic illnesses included diabetes, heart disease, hypertension, osteoarthritis, and bronchial asthma. Compared to the control group, the PD patient group had significantly higher prevalence and severity of depression. These authors also used the World Health Organization Quality of Life Scale—Brief Version (WHOQOL-Bref), a scale that has four subdomains of QOL (physical health, psychological health, social relationships, and environment). In all four subdomains, depression was significantly negatively correlated with QOL within the PD group. One limitation to this study is that the authors did not analyze the relationship between depression and QOL in the non-PD control group. This comparison would have been valuable to determine whether depression in PD is relatively more harmful to QOL than in other medical populations, in addition to being more prevalent. Another weakness to this study is the heterogeneity of the control group in terms of chronic illness, which prevented the authors from matching samples based on duration and severity of illness. Despite these limitations, this study supports the argument that depression in PD is higher than can be explained by chronic illness, and these higher rates of depression ultimately contribute to poorer QOL.

Several other studies have attempted to parse apart the relative strength of factors contributing to QOL using regression analyses. Schrag and colleagues (2000) found that BDI depression score accounted for 54% of the variance in QOL, as measured by a disease-specific QOL measure, the Parkinson’s Disease Questionnaire (PDQ-39). Degree of disability, postural instability, and cognitive impairment were also significant contributors to poor QOL, accounting for an additional 18% of the variance. A similar study also used the PDQ-39 as an outcome measure for QOL, however they expanded their predictor variables to include other NMS (Gallagher et al., 2010). Gallagher and colleagues (2010) found that depression was the strongest
predictor of QOL in multivariate regression analyses (adjusted $R^2 = 0.53$, $p = 0.005$), followed by fatigue severity and autonomic functioning. Another study with a relatively large community-based sample of PD patients ($n = 282$) used a non-disease-specific QOL measure (SF-36) to assess factors relating to QOL (Kuopio et al., 2000). Depression again was a significant predictor in all eight domains of the SF-36, and it accounted for the most QOL variance across seven of the dimensions (ranging from 12% to 28% of the variance). In the physical functioning dimension, clinical stage of PD (H/Y scale) explained the most variance (48%), with depression accounting for an additional 8% of the variance. In summary, depression is a critical outcome variable to assess in PD, due to its multidimensional etiology, its influence from disease progression and functional impairment, and its impact on QOL.

**Apathy in Parkinson’s disease.** Although apathy is often considered related to depression, it is conceptualized somewhat differently in the context of PD. Apathy is essentially a lack of motivation across three main domains: 1) lack of interest in new experience and concern over one’s problems (cognitive), 2) lack of effort, productivity, initiation, and drive (behavioral), and 3) flattened affect and lack of response to positive or negative events (affective) (Kirsch-Darrow, Fernandez, Marsiske, Okun, & Bowers, 2006; Pandya et al., 2008). In recent years, the Movement Disorder Society has called for research exploring apathy as a “disorder of motivation” that deserves more attention within PD studies (Leentjens et al., 2008).

**Prevalence of apathy.** The frequency of apathy in PD has been typically assessed using informant-based rating scales, given that motivation (or lack thereof) is an internal state and clinician ratings may not be accurate due PD patients’ limitations expressing facial emotions (e.g., “masked facies”) (Kirsch-Darrow et al., 2006). There are several scales that have been developed to evaluate apathy in patient populations, with the Starkstein Apathy Scale (SAS)
(Starkstein et al., 1992) recommended for use with PD patients by the Movement Disorder Society task force (Leentjens et al., 2008). The task force also emphasized that the discrepancy between the large amount of research exploring depression in PD and the limited research focusing on apathy is unjustified because apathy symptoms are reported among a majority of PD patients. There is still debate whether apathy should be considered a separate syndrome (see Starkstein & Leentjens, 2008 for a review), or if it should parsimoniously remain classified as a characteristic of other disorders, such as depression and dementia.

Despite the continued discussion of apathy’s place in research and how it should be assessed, prevalence rates of apathy in PD are high, ranging from 38% to 60% in various studies (Pedersen, Larsen, Alves, & Aarsland, 2009; Oguru et al., 2010). One study examined apathy and depression in PD patients and a group of patients with dystonia (Kirsch-Darrow et al., 2006). PD patients had higher frequency and severity of apathy than the dystonia patients (measured by the Apathy Evaluation Scale [AES; Marin, Biedrzycki, & Firinciogullari, 1991]). Apathy was present in 51% of PD patients but only 20% of dystonia patients, and PD patients had significantly higher scores on the AES than the dystonia patients. There were also differences between the two groups when evaluating comorbidity of apathy and depression. Approximately 29% of PD patients exhibited clinically significant apathy scores in the absence of clinically significant depression scores, while none of the dystonia patients demonstrated apathy without depression. The groups had comparable frequencies of depression symptoms alone (4% for PD, 10% for dystonia) and comorbid apathy and depression symptoms (23% for PD, 20% for dystonia).

A slightly different pattern of findings emerged in another population-based study of PD patients, with 38% of the patients showing some symptoms of apathy (Pedersen et al., 2009).
Nearly equal percentages of patients demonstrated apathy without depression (9%) as did with depression (10%). Pedersen and colleagues (2009) used a validated single motivation/initiation item from the UPDRS I to detect apathy rather than one of the longer apathy-specific scales, which may explain the lower prevalence rates compared to the Kirsch-Darrow and colleagues (2006) study. Despite the limitations of using a single item to detect a symptom, their study supports the argument that apathy is common in PD patients and can present independently of depression. Both of these studies highlight the need to assess apathy separately than just in the context of depression, since a notable portion of patients exhibit apathy but do not meet criteria for clinically significant depression scores.

**Pathophysiology of apathy versus depression.** Researchers believe apathy symptoms are due to frontal subcortical dysfunction, similarly to depression (Pluck & Brown, 2002). This hypothesis is supported by presence of apathy symptoms in other neuropsychiatric disorders with similar neurodegenerative processes as PD (e.g., Alzheimer’s disease; Levy et al., 1998). Despite some overlaps in clinical presentation and pathophysiological basis, depression and apathy have subtle differences. Some of these differences are evident in non-PD patient groups. In a study of patients with various neuropsychiatric disorders (left or right hemisphere stroke, probable Alzheimer’s disease (AD), and major depression), apathy and depression were correlated but clinically distinct within and across diagnostic groups (Marin, Firinciogullari, & Biedrzycki, 1994). For example, AD and right hemisphere stroke patients most frequently had elevated apathy scores without depression, while left hemisphere stroke and major depression patients had elevated levels of both apathy and depression. A similar study of patients with various dementia syndromes, including both AD and PD patients, found that apathy and depression were correlated in the PD group but not in any other dementia syndrome groups.
(Levy et al., 1998). Levy and colleagues (1988) also found that apathy and depression were related to different neuropsychiatric symptoms. Apathy was more associated with disinhibition and abnormal motor behavior, while depression was associated with agitation, irritability, and anxiety.

Other research also supports the argument that apathy in PD, like depression, does not represent just “premature social aging” and may be due to a unique pathophysiology. Pluck and Brown (2002) designed a study to further explore Singer’s (1973) observations of limited social functioning in PD patients. They compared PD patients with osteoarthritis patients, arguing that osteoarthritis patients are an appropriate control group because of similar patient age and the chronic, progressive, disabling nature of the disease. There were no significant differences between the two groups regarding degree of disability, however the PD group had clinically significant apathy scores while the osteoarthritis patients showed no evidence of apathy. Their results support the idea that apathy, similarly to depression, is a distinct feature of PD and cannot be solely explained as a reactive or psychological response to motor impairment and subsequent disability.

Another study looked at subtypes of PD with presumed differing pathophysiology and found notable differences between apathy and depression (Moretti et al., 2012). They compared PD patients with akinetic-rigid type and tremor-dominant type, with the former characterized by absence of voluntary movement and the latter characterized by involuntary tremors and movements. The akinetic-rigid patients performed more poorly on cognitive tasks involving the frontal lobe, showed more insight into their condition, had lower depression scores but significantly higher apathy scores. Conversely, the tremor-dominant type patients did better on cognitive tasks, had less insight, higher depression scores but less apathy. These findings
suggest that there is an independent pathophysiological mechanism underlying apathy that may be different from the deteriorating dopaminergic pathways thought to be a pathophysiological contributor to depression in PD. As more investigations continue to tease apart apathy and depression in PD (e.g., Kirsch-Darrow et al., 2006), there is substantial evidence to support studying apathy a distinct feature of PD.

**Apathy and quality of life.** Not surprisingly, there is strong support in the literature for the negative relationship between apathy and QOL. In a study of apathy, depression, and QOL in PD patients (n = 150), Oguru and colleagues (2010) found high overall prevalence rates (60% for apathy, 56% for depression) and similar rates of apathy in the absence of depression (17%) and depression in the absence of apathy (13%) as compared to previously mentioned studies. Both depression and apathy were significantly correlated with patient QOL and UPDRS subscales. Apathy, however, was correlated with H/Y stage and cognitive dysfunction (as measured by the MMSE), while depression was not. Although apathy and depression were both predictors of QOL (as measured by the PDQ-39), there were some nuanced differences between the variables and the PDQ-39 subscales. Variance in apathy scores was mainly explained by cognition and stigma, while depression scores were explained by emotional well-being and communication. Oguru et al. (2010) concluded that while both apathy and depression are related to QOL and disease progression, they can occur independently and may have a differing underlying pathophysiology that is not fully understood.

There is some evidence that apathy may be subjectively more detrimental for QOL in PD, even compared to other NMS. In a large multicenter survey (n = 1,072), Barone and colleagues (2009) used semi-structured interviews to examine a range of NMS in PD patients. NMS were highly prevalent (98.6% of patients), with psychiatric symptoms as the most frequently reported.
Although general psychiatric symptoms were present in 67% of all patients, apathy was present in 31% of PD patients and associated with the worst QOL compared to all other NMS on the PDQ-39.

Another study examined apathy, depression, and QOL in PD patients diagnosed within the past two years (Benito-León, Cubo, & Coronell, 2012). These researchers recruited from 557 patients from 102 outpatient clinics and found similar patterns of prevalence rates to those seen in the Oguru et al. (2010) and Pedersen et al. (2009) studies (overall prevalence rates: 52% apathy, 45% depression, 22% apathy alone, 14% depression alone, 30% comorbid apathy and depression). They used logistic regression models to predict which variables could differentiate between patients that had high versus low QOL (based on cutoff index score) on both a self-reported questionnaire and a QOL visual analog scale. Even after adjusting for significant covariates, including UPDRS motor score, H/Y stage, motor fluctuations, and depression, apathetic patients (based on clinical cut-off score) were nearly 2.5 times as likely as nonapathetic patients to have low QOL on the self-reported questionnaire and 3.6 times as likely to have low QOL on the visual analog scale. This study demonstrates that apathy affects QOL even during early stages of the disease, which again emphasizes the importance of recognizing and measuring apathy as a separate feature of PD and not subsumed as a symptom of depression.

Resilience. In contrast to the previously reviewed research of PD and negative impacts on patients’ lives, another research area within psychology and social science explores how people cope and successfully adjust to health problems to generate more positive outcomes. This study of resilience within psychology and social sciences over the past 50 years represents a shift from a disease model toward a model that accounts for positive adaptation as well. Resilience research reflects this integration of risks and positive influences and emphasizes understanding
what factors help people have successful outcomes, rather than disease-model research, which studies the risk factors that result in poor outcomes.

**Definition of resilience.** The resilience construct was initially conceptualized and explored with children and adolescents that overcame adverse childhood environments (Rutter, 1989; Werner, 1996). Although no single definition exists, researchers generally agree that resilience involves three main characteristics: recovery, sustainability, and growth. *Recovery* refers to how well people can “bounce back” from challenge and stressors, or the ability to return to baseline levels of functioning (Zautra, Arewakisporn, & Davis, 2010; Zautra, Hall, & Murray, 2010). People demonstrating the recovery characteristic of resilience regain psychological and physiological homeostasis after a stressful event. For example, a majority of New York City residents had few or zero posttraumatic stress disorder (PTSD) symptoms during the six months following the September 11th terrorist attacks, which the researchers viewed as quick recovery from an acute stressor (Bonanno, Galea, Bucciarelli, & Vlahov, 2007).

Resilience also involves *sustainability*, or the capacity to maintain psychological health and well-being while continuing forward in the face of challenge, adversity, and daily stressors (Bonanno, 2004; Zautra, Arewakisporn, & Davis, 2010). Sustainability is often measured as the extent to which people continue engaging in positive life pursuits and experiencing positive emotions. A person maintaining low levels of depression following bereavement (Bonanno, 2004) or continuing with average levels of daily physical functioning during a chronic pain episode (Zautra, Hall, & Murray, 2010) demonstrates an ability to sustain well-being through stress. After the recovery from an adverse event and sustainability of meaningful living, resilient individuals often display *growth*, or an enhanced capacity for adaptation (Zautra, Arewakisporn, & Davis, 2010). People may have an enriched understanding of an experience or a new, adaptive
perspective on life, which is similar to the concept of posttraumatic growth or stress-related
growth (Aldwin & Levenson, 2004). Considered altogether, resilience involves recovery from
an adverse event, maintenance of values and purposeful life pursuits, and new learning or
advances as a result of the adversity.

Late life resilience. With the expanding demographic of older adults expected to
compose 20% of the U.S. population by 2030 (Federal Interagency Forum on Aging-Related
Statistics, 2008), some researchers have begun studying resilience towards the end of the
lifespan. Older adults generally experience more stressful life events than younger adults,
including dealing with personal losses, increases in disease vulnerability, and numerous
functional limitations (Allen, Haley, Harris, Fowler, & Pruthi, 2011). Despite these challenges
and declines, a growing body of research has found a “paradox of aging,” with old age often
characterized by various heightened abilities and growth-oriented goals (Bauer & Park, 2010;
Carstensen & Hartel, 2006). Resilience and the related construct of successful aging (Rowe &
Kahn, 1987) often involve the maintenance of psychological well-being in the face of common
and age-specific stressors, such as trauma, loss, or illness.

One consistent finding within mental health and aging research is that many older adults
have good psychological well-being, including high ratings of happiness, self-esteem, and
satisfaction with QOL (e.g., Crocker & Wolfe, 2001; Diener & Suh, 1997; Herzog & Rodgers,
1981; Uhlmann & Pearlman, 1991). Although older adults face declines in physiological and
cognitive functioning, evidence suggests that emotional well-being remains very stable, and it
may even grow more complex and mature as adults reach old age (Carstensen & Hartel, 2006;
Carstensen et al., 2011; Isaacowitz, Charles, & Carstensen, 2000). This emotional stability and
adaptiveness is seen in studies of trauma, with older adults recovering more quickly from PTSD
symptoms (Kato, Asuki, Miyaki, Minakawa, & Nishiyama, 1996) and being three times more likely to demonstrate resilience (as measured by one or zero PTSD symptoms) than younger adults following a traumatic event (Bonanno et al., 2007). Studies of overall prevalence rates also find that older adults have lower PTSD rates and other anxiety disorders than their younger counterparts (Creamer & Parslow, 2008; Wolitzky-Taylor, Castriotta, Lenze, Stanley, & Craske, 2010).

Late life resilience is also evident when comparing older and younger patient’s differential adjustment to illness and health stressors. A recent review of 22 studies of patients with disabilities found an age-related depression trend, with younger patients at higher risk for depression than older patients (Bombardier et al., 2010). Another noteworthy study examined a large group of patients (n = 758) across six different chronic illnesses and found that older patients (>60 years old) had better total mental health scores than middle-aged or younger patients in all psychological diagnostic groups (Cassileth et al., 1984). Similar age-related differences in psychological outcomes are seen in studies of limb amputation (Williamson, Schulz, Bridges, & Behan, 1994), cancer (Williamson & Schulz, 1995), pain (Gibson & Helme, 2001), and heart transplant (Shamaskin et al., 2012). Many of these studies suggest that adaptive coping, emotion regulation, and stress inoculation due to prior experience with health stressors account for the older patients’ comparatively better adjustment.

Although researchers were initially puzzled by these findings, a perspective that is gaining increasing support views aging as the “maintenance of development in the face of cumulative risks” (Ong et al., 2009, p. 1779). This lifespan approach to human development highlights growth and adaptation as characteristics of aging, not only compensation and accommodation. While the basic framework for resilience (recovery, sustainability, growth) is
applicable to all populations, there are important developmental changes with age that should be considered as unique elements of late life resilience.

**Age-related resilience components.** A variety of research has attempted to explain the “paradox of aging,” exploring how psychological well-being is maintained and even strengthened in late life despite losses and declines across numerous domains. The construct of resilience initially conceptualized how children from adverse environments could have adaptive outcomes, and this phenomenon has since been studied in many populations facing different challenges. There has not been, however, an exploration of late life resilience as a qualitatively different construct from that which is applied to younger populations. The following sections integrate developmental theories of aging with new frontiers in the stress and coping literature to suggest unique age-related components of resilience.

*Positivity and meaning-focused coping.* The stress and coping literature is a natural body of research for comparison to resilience. When faced with a stressor, people’s experiences and abilities to cope with that stress partially determine whether they will have an adaptive outcome. Lazarus and Folkman’s (1984) transactional model of stress and coping explains that outcomes depend on initial stressor appraisals and the subsequent type of coping used to address the problem. More specifically, the primary appraisal of a stressor involves evaluating the situation or stressor as a harm, threat, or challenge. During secondary appraisal, people evaluate their resources and abilities to cope with the situation. The primary appraisal of the stressor and secondary appraisal of coping options often interact to determine the emotional effect of the stressor. After the appraisal process, individuals can engage in either problem-focused or emotion-focused coping. Problem-focused coping frequently involves problem-solving strategies (e.g., generating alternatives, weighing costs and benefits), and it is most effective in situations
when specific actions and proximal tasks can change the stressor. Emotion-focused coping, on the other hand, aims to regulate emotions and distress (e.g., selective attention, avoidance, minimization) when a situation cannot be changed through direct action. According to the model, if coping attempts are ineffective or unsuccessful, the appraisal-coping process repeats and can result in chronic stress.

There is some evidence of age differences in coping based on this model. Folkman, Lazarus, Pimley, and Novacek (1987) found that younger adults ($M = 41$ years, $SD$ unavailable) generally used more active, interpersonal, problem-focused methods of coping, while older adults ($M = 68$ years, $SD$ unavailable) used more passive, intrapersonal, emotion-focused forms of coping. The older adults also reported fewer hassles than the younger adults, a finding consistent with other studies demonstrating age-related decreases in stressor frequency (Almeida & Horn, 2004; Charles & Carstensen, 2010) and stressor severity (Aldwin, Sutton, Chiara, & Spiro, 1996). Other research suggests that the experience gained with age plays an important role in the coping process. One study found that age was positively correlated with less perceived control, however older adults did not appear to use more avoidant coping strategies, as would be predicted by feeling less control (Aldwin, 1991). This strategy ultimately lessened the adverse effects of less perceived control, which Aldwin suggested reflected a skill developed out of years of experience learning effective and ineffective coping techniques.

Folkman later identified a shortcoming of the original stress and coping model: It only explained how coping could manage distress and did not account for positive emotions. The revision to her model stemmed from her longitudinal study of caregiving partners of men with AIDS (Folkman, 1997). In this study, she found that positive emotionality played an unexpectedly prominent role in the caregiving and bereavement processes. Folkman suggested
that positive emotions help people find meaning from an event and positively reappraise the situation, instead of repeating the appraisal-coping process. Since this revision, researchers have found that positive emotions and this type of coping, termed *meaning-focused coping*, have an important function in the stress and coping process and are distinct from simply regulating negative emotions (Folkman, 2008; Folkman & Moskowitz, 2000). Meaning-focused coping can occur when people experience distress from a discrepancy between their global meaning (enduring beliefs and valued goals) and situational meaning (initial appraisal of meaning from an event) (Park & Folkman, 1997). This process incorporates people’s beliefs and existential goals to motivate coping and well-being during difficult situations, often through goal revision or reprioritization. Folkman (2008) reviews how one’s meaning-making ability incorporates positive emotions (e.g., positive reappraisal, infusion of ordinary events with positive meaning), but the process can also generate positive emotions out of an unfavorable resolution. Some researchers suggest a connection between positivity and resilience (Ong, Bergeman, Bisconti, & Wallace, 2006; Tugade & Fredrickson, 2007), such that people who can successfully use positive emotions in the coping process have more resilient outcomes. This interplay between positive emotions and coping is at the heart of understanding late life resilience, primarily due to age-related changes in emotion regulation.

In conjunction with Folkman’s (1997) revised model, which created a place for positivity in the stress process, other developmental theories of aging suggest that positive emotions have an especially salient role as we age. An extension of the “paradox of aging” findings includes research that demonstrates general increases in positivity with increasing age (Gross et al., 1997; Mroczek & Kolarz, 1998). In the context of Folkman’s (1997) revised model, this age-related heightened positivity could lead to relative proficiency in meaning-making ability. One
theoretical explanation supporting positivity as mechanism that promotes meaning-focused coping is socioemotional selectivity theory (SST).

SST is a motivational theory of aging suggesting that time perspective, or a sense of how much time people have left to live, is integrally related to how they select goals (Carstensen, Fung, & Charles, 2003). When time does not seem limited, such as when people are younger, Carstensen and colleagues suggest that a “future time perspective” motivates them to seek information and make new social contacts. When time feels limited, which occurs toward the end of the lifespan, people take on a “limited time perspective” and are instead motivated to pursue emotion-focused goals that can be satisfied in the short-term. This theory is supported by reliable and robust age differences in time perspective (Kennedy, Fung, & Carstensen, 2001; Lang & Carstensen, 2002) and pursuit of emotionally satisfying goals (Fredrickson & Carstensen, 1990).

The clear preference for emotion-related goals among older adults is often displayed in social network size and composition. Older adults tend to selectively prune their social networks to discard unimportant relationships, such that they have smaller social networks composed of emotionally close partners (Carstensen et al., 2003). Rooted within SST, an emerging body of research also highlights the extensive role of positive emotion and improved emotion-regulation with age. Older adults prefer, attend to, and remember positive information more so than negative information (Mather & Carstensen, 2005). This positivity effect has been demonstrated in studies of working-memory (Mikels, Larkin, Reuter-Lorenz, & Cartensen, 2005), autobiographical memory (Kennedy, Mather, & Carstensen, 2004), and memory for age-relevant health information (Shamaskin, Mikels, & Reed, 2010). There is substantial evidence in both longitudinal and cross-sectional designs demonstrating this predominance of positive
emotionality among older adults (e.g., Carstensen & Mikels, 2005; Charles, Reynolds, & Gatz, 2001; Scheibe & Carstensen, 2010). Researchers also suggest that older adults demonstrate emotional complexity and improved emotion-regulation abilities, as seen through the co-occurrence of positive and negative emotions (Carstensen et al., 2011; Ong & Bergeman, 2004) and increased stability in emotional experiences (Gross et al., 1997; Röcke, Li, & Smith, 2009).

This age-related increase in positive emotionality can have a direct effect on coping options and ultimately an increased ability to make meaning from adversity. Fredrickson’s (1998, 2001) broaden-and-build model offers an explanation of how positive emotions can facilitate coping with stress. Positive emotions allow people to broaden their scope of attention (Fredrickson & Branigan, 2005), promote flexible and creative thinking (Isen, Daubman, & Nowicki, 1987), and undo the physiological effects of negative emotions (Fredrickson, Mancuso, Branigan, & Tugade, 2000). The broaden-and-build model suggests that over time, these positive emotions help people build a repertoire of physical, social, and intellectual resources that can facilitate future coping (Aron, Norman, Aron, McKenna, & Heyman, 2000; Fredrickson, 2000).

Fredrickson (2000) hypothesized that because positive emotionality promotes broadened thinking and resources, this increases one’s ability to find positive meaning. Additionally, people’s abilities to find positive meaning in turn predict more positive emotionality (Fredrickson, Tugade, Waugh, & Larkin, 2003). This reciprocal relationship between positive emotions and positive meaning creates an “upward spiral” of emotional well-being and resilience (Fredrickson, 2001). Considered altogether, finding positive meaning triggers positive emotions, which subsequently broadens thinking, builds personal resources, and ultimately increases the likelihood of adaptive, meaning-focused coping in the future. Among older adults, this emphasis on positivity and meaning-focused coping presumably enhances their ability to maintain well-
being and make meaning from potentially negative elements of aging (i.e., physical, cognitive, and functional declines). Fredrickson (2001) and others (Ong & Bergeman, 2004; Tugade & Fredrickson, 2007) highlight this ability to utilize positive emotions as a central component of psychological resilience. Given the relationship between positivity and aging, there is good reason to believe this skill is a particularly important contributor to late life resilience.

In summary, SST and supporting evidence of age-related changes in emotion regulation demonstrate the salient role of positivity as people age. The broaden-and-build model outlines how these positive emotions contribute to meaning-focused coping and resilience. Therefore, positive emotions and meaning-making abilities are conceivably very relevant components of late life resilience. Some researchers even argue that positivity not only contributes to resilience, but it also acts as the underlying mechanism of understanding resilience in older adults (Bonanno, Westphal, & Mancini, 2012).

*Goal-flexibility.* Another perspective for understanding coping and well-being involves goals, specifically how people deal with unattainable goals. Although being unable to reach a goal is a common experience across the lifespan, older adults in particular often face unattainable goals due to declines in physical health and cognitive functioning (Wrosch, 2011). Wrosch (2011) and colleagues (Wrosch, Scheier, Miller, Shulz, & Carver, 2003) argue that the ability to disengage from personal goals is an adaptive self-regulation process. The self-regulation of unattainable goals involves two main components: goal disengagement and goal re-engagement (Wrosch, 2011). A person disengages from a goal by withdrawing effort and commitment toward that goal, for example, choosing to stop running after an injury. Goal re-engagement requires shifting efforts to pursue other meaningful goals, such as seeking out a new hobby or interest. This process has similarities to the optimization and compensation components of the
SOC model (Baltes & Baltes, 1990), as well as the role of goal adjustment in Folkman’s (1997) meaning-focused coping.

In addition to the age-related changes in positivity and meaning-focused coping, there is some evidence for older adults’ enhanced abilities in goal adjustment and flexibility. Several studies demonstrate that older adults can disengage from goals more fully than their younger counterparts (Heckhausen, 1997; Wrosch, Bauer, & Scheier, 2005; Wrosch et al., 2003; Wrosch & Heckhausen, 1999). Successful goal disengagement has subsequent benefits, including improvements in physical health (Wrosch, Miller, Scheier, & de Pontet, 2007) and buffering against depressive symptoms (Dunne, Wrosch, & Miller, 2011). Older adults can also more easily accommodate and find new goals to pursue compared to younger adults (Wrosch et al., 2003). There is good evidence that this goal re-engagement is a critical component of adaptive goal-flexibility. Wrosch et al. (2003) found that goal disengagement was associated with increased subjective well-being, but only if older adults could re-engage in other meaningful activities. Another study drew similar conclusions by examining older adults one year after illness onset that required abandonment of physical activities (Duke, Leventhal, Brownlee, & Leventhal, 2002). Those older adults that pursued other goals had higher positive affect than those that did not replace their lost activities. The flexibility required in the disengagement and re-engagement process is consistent with other perspectives of age-related changes in goal adjustment, such as the transition from tenacious goal pursuit to flexible goal adjustment (Brandtstädtter & Renner, 1990). Overall, adaptive self-regulation of unattainable goals has positive effects on well-being. As people age, proficiency in this processes becomes an increasingly important part of maintaining QOL and resilience due to the inevitable developmental constraints on personal goals.
In summary, there is a strong argument for positivity, meaning-making ability, and goal-flexibility as unique components of late life resilience. Age-related changes in emotion regulation and positivity contribute to improved abilities to cope and make positive meaning from adverse situations. Goal-flexibility is an increasingly important skill in later life, and older adults that are able to disengage and re-engage in activities can satisfy goals without extensive demand on resources. These components may be important characteristics of resilience that are unique to older adults. Continued research is necessary, however, to study resilience in late life, understand the variables implicated in the late life resilience process, and learn how these age-related strengths may play a role adjusting to health stressors and disease.

**Resilience measurement.** In exploring the construct of late life resilience, one basic challenge stems from the interdependence of construct conceptualization and assessment. Appropriate measurement depends on a clear understanding of the construct to be assessed, but our understanding of the construct relies upon research and measurement. Although there is basic agreement on the three main characteristics of resilience (recovery, sustainability, and growth), there is still disagreement as to the qualitative nature resilience. Some researchers view resilience as a resource utilized during periods of stress. For example, Aldwin, Sutton, and Lachman (1996) found that 80% of men undergoing a stressor reported drawing resources from a past experience, however only 23% said they drew from a similar stressful experience. The rest of the men used more generalized resources, such as emotion regulation skills that were developed after dealing with a previous stressor.

Resilience is also studied as an outcome, or the result of successful adaptation in the face of adversity (Masten & Wright, 2010). One advantage to this approach is that researchers can more easily focus on single outcomes (e.g., academic achievement, psychological well-being)
and use variable-focused statistical analyses to predict outcomes based on specific risk and protective factors. Other researchers view resilience as an individual resource involving temperament and personality factors (Block & Block, 1980) or as dynamic process that cannot be simplified as an individual trait (Bonanno, 2004; Luthar, Cicchetti, & Becker, 2000). Luther et al. (2000) suggest that confusing terminology partially contributes to the field’s difficulty clarifying the nature of resilience. For example, even researchers that argue resilience is best conceptualized as a process refer to “resilient children,” “resiliency,” or other terms that carry the connotation of resilience as a personality trait or individual attribute. Despite the somewhat misleading terminology, the process approach has strong empirical support within resilience research. Resilience as a process not only accounts for risk and protective factors, but it incorporates how they function to create positive growth outcomes, which is a similar interactive conceptualization seen in stress and coping models (Lazarus & Folkman, 1984).

These differences in how resilience is defined also pose challenges for how it is best measured. If resilience is conceptualized as an individual dispositional trait, it could presumably be measured and observed at any time, not contingent upon whether or not the individual was in a period of high stress that might require resilience. On the other hand, if resilience reflects a dynamic process, researchers could assess within the context of a stressful encounter to better understand how resilience develops. Resilient outcomes, as well, must be measured after a stressful or adverse event. More research is needed to clarify the nature of resilience and how it should be best measured (see Luthar et al., 2000 for a review). While it is important to recognize these larger construct conceptualization challenges in resilience research, the present study will not attempt to comprehensively explore the qualitative nature of the construct. This study will instead take a more applied approach and focus on the commonly used tools for studying
resilience, specifically self-report resilience scales. The current investigation will address the limitations of using resilience scales with an older population, hypothesize about unique age-related components of resilience, and test the impact of these components within an older adult population.

In a recent review of resilience scales (Windle, Bennet, & Noyes, 2011), very few scales have been developed with and validated for use with older adults (See Table 1). Only the Resilience Scale (Wagnild & Young, 1988) was developed initially with exclusively an older adult population, however further analysis of its original development reveals some important weaknesses and limitations. Wagnild and Young (1988) recruited a small convenience sample of Caucasian older women (n = 24) from senior centers who had shown successful adaptation to a major life event. High scores on the Philadelphia Geriatric Center Morale Scale (PGCMS) and active participation in the senior center characterized “successful adaptation,” though it is unclear how the researchers assessed active participation. The women were interviewed and asked to reflect on a loss they had experienced within the past five years. The small sample size and homogeneous sample makeup represent one clear limitation in terms of generalizability to other populations. Another important weakness of the RS is the interview framework that guided participants to reflect on a recent loss. There is still debate whether resilience should be observed in the context of a stressor, or whether it can be assessed in people who have yet to experience significant adversity. In this sense, the RS is only based on characteristics of adaptation that occurred in response to a stressor, but may not include the hypothesized “psychological reserve capacity” elements of resilience in older adults (Smith & Hayslip, 2012; Staudinger et al., 1995).

The Connor-Davidson Resilience Scale (CD-RISC), though not developed with an older adult sample, has received some support in the literature for use with older adults (Table 1). The
subscales, however, are somewhat poorly defined, and there is some evidence that the factor structure may be different with an older adult population. Lamond and colleagues (2008) used the CD-RISC to study resilience in older women, and they found that the *acceptance and tolerability of negative affect* factor emerged as a higher-order factor than compared to the factor structure in the Connor and Davidson (2003) development sample of younger and middle-aged adults. They suggested that perhaps resilience in an older population reflects a different process that involves contributions from acceptance and toleration of negative affect (Lamond et al., 2008). This finding is also consistent with research on affective changes with increasing age (Gross et al., 1997), which lends further support to the hypothesis that positivity and enhanced emotion regulation skills are important contributors to older adult resilience.

On the other hand, the Resilience Scale for Adults (RSA) included older adults in its development sample and has received good support in the literature as one of the highest quality resilience scales (Windle et al., 2011). The RSA is unique compared to the other resilience measures listed in Table 1 for two main reasons. First, the questionnaire was originally developed using a theory-driven approach rather than using qualitative responses from a target population, as was used to develop the RS (Wagnild & Young, 1993). The RSA scale developers followed a qualitative method for scale development (DeVellis, 2003; Kazdin, 2010a); they identified a specific construct definition of resilience, conducted a thorough literature review to generate categories of protective resilience factors, generated a wide range of possible items, and finally winnowed the items down using an expert panel and an exploratory principal components analysis (Hjemdal, 2007).

Second, the RSA scale development process was conducted with specific intention to target the three overarching protective categories based on the longitudinal studies of pioneering
resilience researchers (Garmezy et al., 1984; Rutter, 1989; Werner, 1996): 1) individual
dispositions or attributes, 2) family support and interpersonal relationships, and 3) wider
environmental and social supports. During the literature review of protective resilience factors,
the scale developers identified 15 clusters of protective factors, but they ultimately generated a
six-factor structure scale that included the three fundamental protective factors identified by
previous researchers. Therefore, the six RSA subscales more comprehensively reflect resilience
theory than other resilience scales and subscales. For example, the BRS and ER-89 subscales
target individual protective factors, but they do not measure family or external social support.
The CD-RISC was also closely tied to resilience theory in its development, however Connor and
Davidson (2003) emphasized Kobasa’s (1979) hardiness concept in their conceptualization. This
ultimately led to their resilience construct and subsequent subscales as reflecting an individual’s
stress coping ability (i.e., hardiness) that buffers the effect of stress and negative life events, but
again does not account for family or external social support.

As seen in Table 1, there is a wide range of subscales across the different resilience
measures, which reflects the continued need for consensus in resilience definition and
measurement (Luthar et al., 2000). For the purposes of the present study, the RSA will be used
to measure resilience due to its highly-rated psychometric properties (see scale description in
Methods section) and clear link to the three major categories of resilience factors. The RSA
subscales are also easily interpretable and straightforward (e.g., positive perceptions of self)
compared to other resilience scales, such as the CD-RISC, which seems to have double-barreled
subscale names (e.g., trust/tolerance/strengthening effects of stress).

Given the numerous questions regarding resilience, many researchers emphasize the need
for more longitudinal or cohort-sequential study designs (Zautra & Reich, 2011). This direction
is particularly important for late-life resilience research, because the cumulative life experiences of older adults likely affect how they experience and cope with stress (Eysenck, 1983). Although longitudinal designs may be the most fruitful method for understanding resilience, there is still value in using self-report scales to better understand the resilience construct. Several available resilience scales have adequate psychometric properties and represent an easy and cost-effective method to measure resilience. As previously explained, the present study will use the RSA to assess resilience (Friborg, Hjemdal, Rosenvinge, & Martinussen, 2003), given its theory-driven development, strong psychometric qualities, and comprehensive and easily interpretable subscales. Additionally, there have been no studies to this author’s knowledge that have examined the RSA with exclusively an older population, and it may be valuable to use this scale in assessing the additional components of resilience (i.e., optimism, goal-flexibility, and meaning-making ability) that may be unique to older adults.
Table 1

*Highest Quality Resilience Scales in Windle et al. (2011) Review*

<table>
<thead>
<tr>
<th>Measurement scale</th>
<th>Number of subscales (items)</th>
<th>Development sample</th>
<th>Subscales</th>
<th>Validation studies with older population Y/N</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Resilience Scale for Adults (RSA) (Friborg et al., 2003)</td>
<td>6 (33)</td>
<td>Two adult samples (one outpatient psychiatric sample; n = 59, mean age range 18 – 75 years; one control sample; n = 276; mean age range 25-50 years)</td>
<td>Positive perception of self; positive perception of future; social competence; family coherence; structured style; social resources</td>
<td>N</td>
</tr>
<tr>
<td>The Connor-Davidson Resilience Scale (CD-RISC) (Connor &amp; Davidson, 2003)</td>
<td>5 (25)</td>
<td>Five adult samples (n = 806) (general population and psychiatric outpatient samples; M = 43.8 years, SD = 15.4 years)</td>
<td>Personal competence, trust/tolerance/strengthening effects of stress, acceptance of change and secure relationships, control, spiritual influences</td>
<td>Y Lamond et al., 2009 (n = 1,395, M = 73 years, SD = 7.2 years) Montross et al., 1996 (n = 205, M = 80.4 years, SD = 7.5 years)</td>
</tr>
<tr>
<td>Scale</td>
<td>Year</td>
<td>Sample Size</td>
<td>Sample Characteristics</td>
<td>Main Constructs</td>
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<tr>
<td>-------------------------------------------</td>
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<tr>
<td>The Ego-Resiliency</td>
<td>1996</td>
<td>4 (20)</td>
<td>Three adult samples (n = 594; mean age range 18 to 48 years)</td>
<td>Confident optimism; productive and autonomous activity; interpersonal warmth and insight; skilled expressiveness</td>
</tr>
<tr>
<td>Psychological Resilience</td>
<td>2008</td>
<td>3 (19)</td>
<td>Sample drawn from secondary data analysis (n = 1,847; mean age range 50 – 90 years)</td>
<td>Self-esteem; personal competence; interpersonal control</td>
</tr>
<tr>
<td>The Resilience Scale</td>
<td>1988</td>
<td>2 (25)</td>
<td>Female adults (n = 24; M = 78 years, SD unavailable)</td>
<td>Acceptance of life and self; Individual competence</td>
</tr>
<tr>
<td>Resilience Scale</td>
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<tr>
<td>Wagnild &amp; Young, 1993 (n = 810, M = 71 years, SD = 6.5)</td>
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<tr>
<td>Wagnild &amp; Young, 1988 (n = 39, M = 71 years, SD = 7.9)</td>
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<tr>
<td>Wagnild &amp; Young, 1991 (n = 43, M = 73 years, SD = 11.7)</td>
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<tr>
<td>The Brief Resilience Scale</td>
<td>2011</td>
<td>1 (6)</td>
<td>Four adult samples (n = 354) (two student)</td>
<td>Individual ability to bounce back or recover from stress</td>
</tr>
</tbody>
</table>
samples, two behavioral medicine samples; mean age range 19-63 years

| al., 2008) | samples, two behavioral medicine samples; mean age range 19-63 years |

“Quality assessment based on ratings of content validity, internal consistency, criterion validity, construct validity, reproducibility agreement, reproducibility reliability, responsiveness, floor and ceiling effects.”
**Resilience in Parkinson’s disease.** Resilience in PD has only recently been gaining attention as an area of research. One qualitative study interviewed PD patients, other progressive neurological diseases, and their caregivers to determine which demographic, disease factors, and coping strategies contributed to better adjustment (total n = 30; 28-50 years old, n = 10; 51-70 years old, n = 16, 70+ years, n = 4) (McCabe & O’Connor, 2012). Participants were split into two groups (high and low adjustment) based on self-reported QOL and score on a mood measure, although the cut-off criteria for high or low QOL or mood were not clearly indicated. The researchers conceptualized “resilient participants” as those who were in the high-adjustment group. The structured interview questions generally focused on adjustment mechanisms, coping strategies, and resources used by patients and families. For both the high and low adjustment groups, social support was reported most helpful in coping with the illness. There were also some notable differences between the two groups regarding positivity; having a positive attitude was frequently cited as a useful strategy in the high-adjustment group, but not cited by any participants in the low-adjustment group.

Another important distinction between the two groups was how they used social support. The high-adjustment group used their social support to make changes to their lives that would enhance enjoyable experiences (e.g., frequent family visits to increase social interaction), while the low-adjustment group used their social support for instrumental needs (e.g., providing assistance around the house). One major limitation of this study is the small sample size (n = 30; 17 patients, 13 caregivers). Not only does this small sample limit generalizability, but the researchers could not make any comparisons across patient groups due to even smaller disease group subsamples (Motor neurone disease, n = 1; Huntington’s disease, n = 1; multiple sclerosis, n = 7; PD, n = 8). Nonetheless, this study highlighted the importance of positivity and using
social support to make meaningful life adjustments as importance elements of coping with the illness.

Another recent study examined the relationships between resilience, disease severity, disability, QOL, and NMS in a sample of PD patients (n = 83) (M age = 66.3 years, SD = 10.6 years) (Robottom et al., 2012). They conceptualized resilience as a measurable “individual trait” that reflects an ability to “spring back in the face of adversity.” They used the 15-item Resilience Scale (RS; Wagnild & Young, 1993), which as previously explained, has good psychometric support and is a commonly used resilience scale. Resilience was significantly correlated with less disability (performance on ADLs and IADLs) and better QOL (SF-12), but not correlated with disease severity (UPDRS total and motor). Regarding NMS, resilience was significantly correlated with overall less psychiatric symptom burden, including less depression, anxiety, somatization, apathy, and fatigue. Lastly, higher resilience scores were also correlated with personality features of greater optimism and less pessimism.

Several important conclusions can be drawn from the Robbotom et al. (2012) study. First, resilience was unrelated to disease severity, but it was associated with less disability and better QOL. This finding supports the idea that resilience does reflect some stable individual feature that is related to disease adjustment but not necessarily disease progression. Robottom and colleagues (2012) argued that resilience might protect patients from disability and poor QOL, serving as a buffer against the known detrimental effects of PD. Another notable finding was the correlation between resilience and positivity. This result is consistent with the McCabe and O’Connor study (2012) and previous research highlighting the important role of positivity in aging (Carstensen et al., 2003, Mather & Carstensen, 2005). Robottom and colleagues (2012)
note that the correlations between resilience and optimism were strong (r = 0.57, p < .001), but not high enough to suggest the scales were measuring the same latent construct.

The Robottom et al. (2012) and McCabe and O’Connor (2012) studies provide useful building blocks for continued research in resilience in PD. Both studies highlight positivity as important components that are related to QOL and generally better outcomes. McCabe and O’Connor (2012) also suggest that using social supports for assistance with goal adjustment is associated with better outcomes. The major limitations of these studies, however, lie within their methodology. The resilience construct is poorly defined in McCabe and O’Connor’s (2012) study, and although Robottom and colleagues (2012) used a common resilience scale, there are unanswered questions as to whether these scales comprehensively assess resilience in older populations. Additionally, Robottom et al. (2012) limited their analyses to include only correlations, and their findings could have been more informative by using additional sophisticated statistical techniques.

**Statement of the problem.** The previously reviewed literature emphasizes the clear need to better understand resilience in an older population. By integrating ideas from developmental theories of aging with the field’s current understanding of the resilience construct, there is good support for late life resilience to stand as a unique construct encompassing different components than resilience in younger populations. These hypothesized unique components include positivity, goal-flexibility, and meaning-making ability. Therefore, late life resilience may not be adequately assessed with current measurement tools, given that many of the tools were not developed while considering these developmental changes.

**Rationale.** Parkinson’s disease is an appropriate and potentially useful patient population in which to study resilience. The generally older patient group faces many challenges with
adjustment to their illness, including some mental health issues that have a pathophysiological etiology. Additionally, there is good evidence that QOL and mental health outcomes are modifiable and cannot be solely predicted by disease progression or motor impairment. There is also a small but growing body of resilience research in older populations, and very limited research on resilience in PD. A project that can explore both the construct of late life resilience and provide more information about positive adjustment in PD patients will address important gaps in the literature. Therefore, the present study investigates the relationships between PD NMS and functional impairment, mental health, and resilience. More specifically, this project studies whether resilience moderates the relationship between PD NMS and functional impairment, and mental health outcomes. Resilience was measured both with a validated resilience scale and with the hypothesized components of resilience that are unique to the older population. Multiple moderation and hierarchical multiple regression analyses will determine whether the hypothesized late life resilience components account for some unique variance in the relationship between PD NMS, functional impairment, and mental health outcomes.

**Hypotheses.** This study has two related but distinct goals in understanding resilience in a PD population. The first goal is to establish the relationship between PD NMS and functional impairments, resilience, and mental health outcomes. The second goal is to determine whether late life resilience involves other features not captured with a standard resilience scale. See Figure 1 for a theoretical conceptualization of hypotheses.

**H1:** PD NMS, functional impairment, and disease symptom-related QOL will be significant predictors of poorer mental health/adjustment-related QOL outcomes.

**H2:** Resilience, as measured by a standard resilience scale, will moderate the relationship between PD NMS, functional impairment, and disease symptom-related QOL and
mental health/adjustment-related QOL outcomes. Patients with greater resilience will have a weaker relationship between their PD NMS, functional impairments, and disease symptom-related QOL and mental health/adjustment-related QOL outcomes.

**H3**: The variables of positivity, goal-flexibility, and meaning-making ability will account for a significant amount of variance in the relationship between PD NMS, functional impairment, and disease symptom-related QOL and mental health/adjustment-related QOL outcomes, above and beyond the variance explained by the standard resilience measure.
Figure 1. Theoretical conceptualization of hypotheses tested through proposed multiple moderator model.
An underlying theme within this project is to explore the relationship between age and resilience, however the previously reviewed literature highlights several challenges in this investigation. First, most resilience scales were not developed or validated for use with an older population. Second, there is compelling evidence within the developmental literature to suggest that the theoretical construct of resilience contains unique components in an older population, which are not currently incorporated into existing resilience scales. Although an ideal study might explore the relationship between age and resilience using a sample of adults across the lifespan reporting on a single, widely-applicable scale, no such resilience measure exists that is indicated for use across the entire lifespan (Windle et al., 2011). Therefore, the present study will focus specifically within an older population to determine whether additional resilience components do, in fact, account for unique variance above and beyond the variance captured by a standard resilience measure. In an effort to capture the widest age range possible, the study will not limit the age-range of PD patients eligible to participate, and age will be analyzed as part of a secondary hypothesis.

H4: Age will moderate the relationship between the unique age-related components of resilience and the standard resilience scale. As patient age increases, the variables of positivity, goal-flexibility, and meaning-making ability will account for significantly more variance in the relationship between PD NMS and functional impairments and mental health/QOL outcomes.

Method

Participants

Participants in this study were recruited through the VCU Parkinson’s and Movement Disorders Center (PMDC) in Richmond, Virginia. Upon IRB approval to conduct the present
study (IRB #HM14988), recruitment involved the IRB approved advertisement shared with collaborators in the following community organizations as well as the PMDC website and listserv: the Southeast Parkinson’s Disease Research, Education and Clinical Center at the Hunter Holmes McGuire Veteran’s Medical Center, the Richmond Chapter of the American Parkinson’s Disease Association (APDA), and the APDA Information and Referral Center at the University of Virginia. Advertising was utilized with the goal of reaching the widest audience possible within the movement disorders community, including individuals typically underserved by movement disorder specialists. In addition to advertising through community organizations, Dr. Lageman, the PMDC’s clinical neuropsychology core director, recruited patients with PD from the VCU Parkinson’s and Movement Disorders Center (VCU PMDC) by discussing the study with patients who had been identified from review of VCU PMDC neuropsychological evaluations included in the PMDC Neuropsychological Data Collection Registry (IRB # HM13254). Eligible individuals had a confirmed medical diagnosis of PD. The populations eligible to participate in this study were adults, ages 21-90+. Exclusion criteria included: individuals with other movement disorders (e.g., Essential Tremor, Huntington’s, Dystonia, etc.), and individuals who were unable to speak and understand English.

Power analyses are necessary to determine the required sample size for a study, given certain parameters about the study design, including desired effect size. In multiple regression analyses, Cohen’s $f^2$ is used as an effect size measure, which essentially equals the unique variance explained by the interaction term in moderation divided by the sum of the error and interaction variables (Cohen, 1988). The effect sizes of 0.02, 0.15, and 0.35 indicate small, medium, and large effects, respectively. In the present study, an *a priori* power analysis was used to calculate the minimum sample size required in order to detect a medium effect size and 80%
power ($\alpha = .05$, $1 - \beta = .80$). These parameters were based on Cohen’s (1992) recommendations that studies should have an 80% probability of detecting an effect when one exists, with no more than 20% probability of making a Type II error ($\beta = .20$). It is difficult to estimate the expected effect size for the proposed study, given that the only study examining resilience and PD conducted only correlations and did not involve regression analyses. In other PD studies that have predicted mental health outcomes based on disease-specific variables (e.g., disease progression, motor impairment), effect sizes in ranged from medium (Kuopio et al., 2000) to large (Oguru et al., 2010). After establishing the desired medium effect size, significance level ($p < .05$), and power (80%), the necessary sample size was 131 participants. This sample size was based upon the maximum number of predictors and control variables in any of the statistical analyses (13 potential predictors in most comprehensive model). The study sought to recruit 150 participants to account for potential attrition during survey completion.

**Procedure**

Participant recruitment occurred between April 2013 and October 2013. The study was advertised as a web-based survey, with paper copies made available upon request. Patients who chose to complete the survey electronically signed an online waiver of documentation of consent to approve using an online web-based survey as the primary data collection tool. They read a statement that outlined the purpose of the study, the risks involved, reminded them that their participation was voluntary, and granted them permission to end the study at anytime.

Participants also read a statement describing the use of protected health information (PHI) in this study, including the type of information collected, the restriction of access to this data to all but necessary study personnel, reasons why this information represented the minimum necessary to complete the study, and the security precautions in place to protect PHI. Participants either
signed (paper questionnaire) or checked a box (electronic questionnaire) indicating that they agreed with these statements before completing the questionnaire. Patients entered their data into an electronic project database, which was protected with a complex password and stored on a secure network behind a VCU firewall (RedCap). The electronic project database and scanned files were secured to be kept indefinitely. If participants requested a paper copy of the survey to complete, the completed physical copies of the data were kept in a locked office and locked file cabinet. The physical copies were destroyed once the data was scanned and entered into the online survey database.

The majority of the participants learned about this study electronically and completed the web-based survey in their homes. If requested, paper copies were mailed for participants to complete in the privacy of their homes. The primary researcher on the study facilitated sending the paper survey, a consent form, and a stamped and addressed return envelope to the requesting individual. If individuals wished to complete the survey at the PMDC, they were provided a computer in a private room. There was no compensation for participation in this study. The survey required 45-60 minutes to complete.

**Measures**

The survey contained ten questionnaires intended to comprehensively assess the hypothesized PD, resilience, and psychologically-related variables. Furthermore, several spirituality-related items from the CD-RISC (Connor & Davidson, 2003) and an illness uncertainty item (Rybarczyk et al., 2007) were included to analyze possible additional effects from these variables. The CD-RISC items were summed and averaged to create a spirituality composite score. Basic demographic information was also gathered for all patients, including age, sex, race, marital status, income level, education level, depression history, duration of time
since symptoms begin, and duration of time since diagnosis. The instruments are described below and listed in the Appendix.

**The Resilience Scale for Adults (RSA; Friborg et al., 2003; Friborg et al., 2005).** The 33-item RSA measures the protective resources that promote resilience in adults. The RSA has six factors: perception of self, perception of future, social competence, structured style, family coherence, and social resources. Two separate reviews of resilience scales rated the RSA as one of the highest quality scales (Ahern, Kiehl, Sole, & Byers, 2006; Windle et al., 2011). As previously mentioned, the RSA has good conceptual support as a tool to measure resilience, because the six factors of the scale correspond closely to the three main categories of resilience outlined by early resilience researchers: dispositional attributes, family cohesion and support, and external support systems (Garmezy et al., 1984; Werner, 1993). This scale has also received some support for use in a medical population (White, Driver, & Warren, 2008).

The RSA has been modified into several versions with differing item numbers and item-response styles (e.g., 37- and 33-item RSA with five point semantic-differential scale format). Despite some decreases in reliability with using the semantic-differential scale format, research demonstrated that the semantic version had better model fit and unidimensionality (Friborg, Martinussen, & Rosenvinge, 2006). The current version of the RSA involves rating items on a 5-point semantic differential scale. Each item contains a stem with two responses at either end of the scale (e.g., “In difficult periods I have a tendency to: view everything gloomy–find something good that helps me strive”). The participant marks one of the five boxes indicating how he or she has felt overall for the past month.

The RSA has adequate psychometric properties, as demonstrated in numerous studies (Friborg et al., 2003; Friborg et al., 2005; Hjemdal, 2007). Hjemdal (2007) reported that in the
initial scale development, the RSA had good internal consistency reliability ($\alpha = .93$), and satisfactory alpha scores have been found in other validation studies ($\alpha = .76$ to .87) (Friborg et al., 2005). The RSA also has adequate test-retest correlations (4 months), ranging from $r = .69$ to .84 in an adult outpatient sample (Friborg et al., 2003). The six-factor structure has been demonstrated in several studies using exploratory and confirmatory factor analyses (Friborg, Hjemdal, Martinussen, & Rosenvinge, 2009, Hjemdal, Friborg, Stiles, Rosenvinge, & Martinussen, 2006). The RSA has good predictive validity as well; one study found that RSA scores could predict psychiatric symptoms after exposure to a stressful life event, suggesting that resilience may buffer or protect against negative outcomes (Hjemdal et al., 2006).

The RSA also has adequate convergent and discriminant validity. It correlated positively with the Sense of Coherence Scale (SOC; Antonovsky, 1993) (subscale correlations ranged from $r = .29$ to .75, $p < .001$) and negatively with the Hopkins Symptom Checklist-25 (HSCL; Rickels, Lipman, Garcia & Fisher, 1972) (subscale correlations ranged from $r = -.19$ to -.61, $p < .001$) (Friborg et al., 2003). Another study using a previous five-subscale version of the RSA (Friborg et al., 2005) established convergent and discriminant validity by using the Big Five personality factors (McCrae & Costa, 1997). Perception of self and perception of future correlated strongly with emotional stability ($r = .79$ and .57, respectively), social competence was correlated with extroversion ($r = .58$) and agreeableness ($r = .59$), and structured style was correlated with conscientiousness ($r = .83$). Although the factors were inter-correlated (ranging from $r = .31$ to .57), there were clear patterns of stronger and weaker correlations between the RSA factors and Big Five personality factors. Resilience scores were also positively correlated with scores on social intelligence measures and not significantly related to cognitive intelligence, which demonstrates additional convergent and discriminant validity.
Another unique element of the RSA is that it provides some clarity regarding a debated topic in resilience research: Is resilience more than simply the absence of pathology (Sroufe, 1997), and if so, do resilience measures assess beyond the latent continuum of vulnerability and psychopathology (Friborg et al., 2009)? If researchers cannot psychometrically differentiate between resilience as the absence of pathology and resilience as fostering psychological growth (Carver, 1998), they risk interpreting scores on resilience and vulnerability measures as positive and negative characteristics of mental health within the same underlying dimension. A recent study by Friborg and colleagues (2009) investigated this question by performing a second-order factor analysis on the primary factor scores from subscales of resilience and psychopathology/vulnerability. Two second-order factors emerged, with the majority of the RSA subscale factors loading onto a different factor than psychopathology/vulnerability. They also examined interactions between the RSA and psychopathology/vulnerability in hierarchical regression analyses and determined that the RSA contributed uniquely to the model. Thus, the RSA seems to measure the resilience construct as conceptually different than the operationalization of vulnerability and psychopathology. This distinction represents an important step forward in resilience research by providing a measure that adequately reflects the literature’s understanding of the construct as involving recovery, sustainability, and growth (Zautra, Arewakisporn, & Davis, 2010).

**Sense of Coherence Scale (SOC-13; Antonovsky, 1993).** The SOC-13 is a 13-item scale that measures one’s global orientation towards feeling confident that one’s environment is predictable and that things will work out as can be reasonably expected (Antonovsky, 1993). The SOC-13 is composed of three factors: comprehensibility, or the belief that the stimuli deriving from one’s internal and external environments in the course of living are structured,
predictable, and explicable; manageability, or the belief that resources are available for one to meet the demands posed by these stimuli; and meaningfulness, the belief that these demands are challenges, worthy of investment and engagement in an effort to make meaning (Antonovsky, 1993). Research demonstrates that the two factors of comprehensibility and manageability are highly correlated with the SOC total (r = .98 to 1.00), while the meaningfulness factor is significantly but slightly less correlated (r = .82) (Feldt et al., 2007). Items are rated on a 7-point semantic differential scale with two opposite anchoring phrases (e.g., “How often do you have the feeling that there’s little meaning in the things you do in your daily life?” 1 = never, 7 = always). Five of the items are negatively worded to avoid acquiescent response bias.

The SOC-13 has adequate psychometric properties. In a review of 127 studies that have used the SOC-13, the scale had acceptable internal consistency reliability (α = .70 to .92) and temporal stability (α = .78 to .54 between 1 and 10 years). Construct validity has been established through studies using factor analyses, and although there is some evidence for a one-factor or five-factor scale structure (Eriksson & Lindstrom, 2005), the three-factor solution is generally best supported in the literature (Feldt et al., 2007). The SOC-13 also has good criterion and predictive validity. Eriksson and Lindstrom’s (2005) review summarizes numerous studies that show positive correlations between the SOC-13 and optimism, self-esteem, and general health, as well as negative correlations between the scale and depression and anxiety. Additionally, several studies have demonstrated that scores on the SOC-13 can predict patient outcomes after orthopedic and bariatric surgeries (Ray, Nickels, Sayeed, & Sax, 2003; Rister, Andersson, Johansson, Johansson, & Ponzer, 2000).

**Tenacious Goal Pursuit/Flexible Goal Adjustment scales (TENFLEX; Brandtstädter, & Renner, 1990).** The TENFLEX is a 30-item scale intended to measure
peoples’ assimilative and accommodative tendencies on a dispositional level. These two complementary types of coping involve: a) transforming circumstances in accordance with personal preference (assimilation), and b) adjusting personal preferences to situational constraints (accommodation) (Brandtstädter, & Renner, 1990). According to the scale developers’ theoretical formulations, assimilative coping strategies correspond to tenacious goal pursuit tendencies, while accommodative coping strategies correspond to flexible goal adjustment. Items are rated on a 5-point Likert scale, and participants rate the degree to which they agree with each statement (e.g., “To avoid disappointments, I usually don’t set my goals too high”, -2 = strongly disagree, 2 = strongly agree). There are 13 reverse items in the scale to avoid acquiescent response bias. The 30 items are split into two 15-item scales: Tenacious Goal Pursuit and Flexible Goal Adjustment.

Initial validation studies demonstrated that the TENFLEX has adequate internal consistency reliability for the flexibility scale ($\alpha = .83$, item-total correlations ranged from $r = .35$ to .60) and the tenacity scale ($\alpha = .80$, item total correlations ranged from $r = .30$ to .59) (Brandtstädter, & Renner, 1990). Flexible goal adjustment and tenacious goal pursuit also had very low variance overlap ($r = .06$), indicating that they reflect distinct constructs. Both scales had good convergent and discriminant validity. Flexible goal adjustment and tenacious goal pursuit were significantly negatively correlated with depression ($r = -.41$ and -.17) and significantly positively correlated with life satisfaction ($r = .36$ and .26) and optimism ($r = .53$ and .28). There is also evidence of an age-related change in coping tendencies, such that there is a transition from assimilative to accommodative tendencies with increasing age (Brandtstädter, & Renner, 1990). A cross-sectional study of 890 adults divided into five cohorts (30 to 60 years old) demonstrated a significant main effect of age cohort, with tenacious goal pursuit scores
decreasing \((F(4, 865) = 2.92, p < .05)\) and flexible goal adjustment scores increasing \((F(4, 862) = 6.09, p < .01)\) with age. These findings are consistent with the previously reviewed research suggesting that goal-flexibility is an important age-related shift in coping mechanisms that can reflect a unique component of resilience among older adults.

**Nonmotor Symptoms Questionnaire (NMSQuest; Chaudhuri et al., 2006).** The NMSQuest is a 30-item questionnaire targeting 10 different domains of PD-specific nonmotor symptoms. The domains are: gastrointestinal tract, urinary tract, sexual function, cardiovascular, apathy/attention/memory, hallucinations/delusions, depression/anxiety/anhedonia, sleep/fatigue, pain, and miscellaneous (e.g., weight loss). Respondents are instructed to respond “yes” or “no” as to whether they have experienced each symptom within the past month.

The NMSQuest has received good empirical support in the literature as one of the first formal assessments of NMS in PD (Martinez-Martin et al., 2007). It has adequate specificity and sensitivity, with recent study demonstrating 71.8% sensitivity for clinically significant non-motor problems (i.e., those serious enough to warrant treatment) and 88.5% specificity across items (Romenets et al., 2011). The NMSQuest can distinguish between PD patients and a control group based on median total NMS scores (PD patient median NMS score = 9 (interquartile rank, 5-13), control group median NMS score = 4 (interquartile rank, 2-8); Mann-Whitney test, \(p < .0001\)) (Chaudhuri et al., 2006). NMSQuest scores also correspond to other expected disease indicators. For example, higher NMSQuest scores were significantly correlated with H/Y stage \((r = .31, p = .0006)\), though scores were unrelated to age, gender, or PD subtype. Lastly, the NMSQuest has good face and content validity, with 75% of patients and 80% of caregivers reporting that the items in the NMSQuest would improve their physician’s ability to treat their PD (Chaudhuri et
al., 2006). Over 90% of patients and caregivers reporting the issues were relevant for their day-to-day lives.

**The Functional Independence Measure-Self-Report (FIM-SR; Keith, Granger, Hamilton, & Sherwin, 1987).** The FIM assesses physical and cognitive disability, as well as the associated burden of care. The original FIM was developed for administration by an independent rater, typically a physician, nurse, or therapist, however it has been validated for use as a self-report version as well (Grey & Kennedy, 1993). The 18-item scale contains six subscales: self-care (e.g., feeding, grooming), sphincter control (e.g., bladder and bowel movement), mobility (e.g., transferring in and out of bed), locomotion (e.g., walking), communication (e.g., comprehension, expression), and social cognition (e.g., social interactions, memory). For each item, respondents can rate their level of independence on a 7-point Likert scale (1 = total assistance needed, 7 = totally independent).

The FIM-SR has not yet been studied with PD patients specifically, although it has been used extensively in rehabilitation medicine and is considered one of the highest quality disability assessment tools (Furlan, Noonan, Singh, & Fehlings, 2011). It has been validated for use with similar patient populations to PD, for example patients with neuromuscular disease and chronic pain (Jensen, Abresch, & Carter, 2005). Another validation study used a sample of spinal cord injury (n = 84) and amputation (n = 38) patients, finding that internal consistency reliability of the FIM-SR total score was adequate both pre- and post-treatment ($\alpha = .95$ and .94 for spinal cord injury patients; $\alpha = .57$ and .87 for amputation patients) (Masedo, Hanley, Ehde, & Cardenas, 2005). The test-retest coefficients of scores at pre- and post-treatment were adequate for the spinal cord injury patients ($r = .89$, $p < .005$) but comparatively low for the amputation patients ($r = .47$, $p < .005$), which the researchers suggest may have been due to restricted range
of scores and ceiling effects. In a study with neuromuscular disease and chronic pain patients (n = 141), the FIM-SR demonstrated good convergent validity with significant correlations between the Short Form Health Survey (SF-36) physical functioning scale and the FIM-SR self-care (r = .38), mobility (r = .41), locomotion (r = .49), and motor scales (r = .42) (Jensen et al., 2005). Additionally, the SF-36 social functioning scale was significantly correlated with the FIM-SR communication (r = .30) and social cognition scales (r = .25).

**Starkstein Apathy Scale (SAS; Starkstein et al., 1992).** The SAS is a 14-item scale that measures an individual’s degree of apathy, specifically targeting the diminished motivation, behavioral, cognitive, emotional, and insight aspects of apathy. The items are phrased as questions to be answered on a 4-point Likert scale (e.g., “Are you indifferent to things?” 0 = not at all, 3 = a lot), with several items worded in the positive direction and reverse scored (e.g., “Do you have plans and goals for the future?” 0 = a lot, 3 = not at all). Responses are summed for a total score. In a recent review of apathy rating scales, the Movement Disorder task force reported that the SAS was the most appropriate psychometric tool for assessing apathy in PD patients (Leentjens et al., 2008).

The SAS has acceptable psychometric properties with PD patients. In the original scale validation study with PD patients, the SAS had adequate internal consistency reliability (α = .76), inter-rater reliability by two independent raters (r = .81, p < .01), one-week test-retest reliability (r = .90, p < .01), and 66% sensitivity and 100% specificity using a cut-off score compared with neurologist ratings (Starkstein et al., 1992). In a more recent study with 212 PD patients, the SAS had acceptable internal consistency reliability (α = .69), and most items had good item-total correlations (r > .30, p < .0005) (Pedersen et al., 2012). Although one item had a negative and nonsignificant correlation with the total score (“Are you concerned about your condition?”),
there has not yet been enough psychometric research to warrant a modified 13-item SAS. The SAS has a two-factor structure, with Factor 1 representing cognitive-behavioral aspects of apathy (α = .74) and Factor 2 representing general apathy including aspects of insight (α = .52). Lastly, the SAS has adequate discriminant validity with other psychological and PD-specific scales. In the Pedersen and colleagues (2012) psychometric study, the total SAS score had weak to moderate correlations with the Mini Mental State Exam (r = -.17, p < .05) and the Unified Parkinson’s Disease Rating Scale motor subscale (r = .21, p < .005). It also had a significant but relatively weak correlation with the Montgomery-Aasberg Depression Rating scale (r = .25, p < .005), which is consistent with previous research emphasizing the conceptual and clinical differences between depression and apathy.

**Parkinson’s Disease Questionnaire (PDQ-39; Peto, Jenkinson, & Fitzpatrick, 1998).** The PDQ-39 is a 39-item QOL measure for PD. The scale has eight discrete QOL domains: mobility, activities of daily living, emotional well-being, stigma, social support, cognitions, communication, and bodily discomfort (Jenkinson, Fitzpatrick, Peto, Harris, & Saunders, 2008). Respondents rate each item reflecting the degree of task difficulty he or she experienced within the past month due to their PD (e.g., “Due to having Parkinson’s disease, how often during the last month have you avoided situations which involve eating or drinking in public?”). Item responses are on a 5-point scale (0 = never, 1 = occasionally, 2 = sometimes, 3 = often, 4 = always (or cannot do at all, if applicable). Scores for each dimension are summed and then transformed to a scale from 0 to 100 in order to ease comparisons across domains (0 = no problem at all, 100 = maximum level of problem).

The PDQ-39 has adequate psychometric support through numerous validation studies (see Jenkinson et al., 2008 for a review). In a study surveying with PD patients, internal
consistency reliability was adequate across all domains at Time 1 (n = 227; $\alpha = .66$ to .95), and it remained adequate at a six-month Time 2 follow-up (n = 223; $\alpha = .73$ to .95). Respondents at Time 2 were also requested to complete a second copy of the PDQ-39 within three to six days after completing the first survey. Of those that completed this second questionnaire within three to six days (n = 167), test-retest reliability was acceptable ($r = .68$ to .94, $p < .001$). Construct validity was also supported with many of the scale domains correlating with relevant scales from the SF-36: Social Support (PDQ-39) correlated with Social Function (SF-36) ($r = -0.34$, $p < .001$); Mobility (PDQ-39) correlated with Physical Function (SF-36) ($r = -0.80$, $p < .001$); Activities of Daily Living (PDQ-39) correlated with Role Limitations due to physical problems (SF-36) ($r = -0.36$, $p < .001$); Emotional Well-being (PDQ-39) correlated with Mental Health (SF-36) ($r = -0.71$, $p < .001$); Bodily Discomfort (PDQ-39) correlated with Pain (SF-36) ($r = -0.66$, $p < .001$). Correlation coefficients were negative due to the different directions in which the PDQ-39 and SF-36 scales are scored.

The Life Orientation Test-Revised (LOT-R; Scheier, Carver, & Bridges, 1994). The LOT-R is a 10-item scale that was developed to measure an individual’s degree of dispositional optimism. There has been some disagreement among researchers whether the LOT-R has one or two dimensions (optimism alone versus optimism and pessimism) (Herzberg, Glaesmer, & Hoyer, 2006). The original validation study of the LOT-R suggested that the scale should be treated as unidimensional (Scheier et al., 1994), however recent investigations have lent support to a bidimensional factor structure with optimism and pessimism as separate subscales (Glaesmer et al., 2012; Herzberg et al., 2006; Kubzansky, Kubzansky, & Maselko, 2004). There is also evidence that age may moderate the relationship between the two factors, such that optimism and pessimism become more independent of each other with increasing age (Herzberg et al., 2006).
The LOT-R consists of three items that assess optimism (e.g., “In uncertain times, I usually expect the best”), three items that assess pessimism (e.g., “I rarely count on good things happening to me”), and four filler items (“e.g., “It’s easy for me to relax”). Respondents indicate the degree to which they agree with each item on a 5-point Likert scale (1 = strongly disagree, 5 = strong agree). The scores of the optimism and pessimism items are separately summed to generate two subscale scores.

The LOT-R has adequate psychometric properties. In the original validation study, psychometric analyses were conducted with the six main scale items, but the four filler items were removed from analyses (Scheier et al., 1994). Item-scale correlations ranged from .43 to .63, which suggested that items were partially measuring the underlying construct but were not redundant with other items. The LOT-R also demonstrated adequate internal consistency reliability for the six items (α = .78) and generally good test-retest reliability over 4 months (r = .68), 12 months (r = .60), 24 months (r = .56), and 28 months (r = .79). In a more recent psychometric evaluation, the LOT-R had good internal consistency reliability for both the optimism (α = .70) and pessimism (α = .74) subscales, while the correlations between the two subscales was low (r = -.20, p < .001) (Glaesmer et al., 2012). Convergent and divergent validity were established between the LOT-R and other psychological scales. The optimism subscale was positively correlated with life satisfaction (General Life Satisfaction Module; Henrich & Herschbach, 2000) (r = .44, p < .001) and self-reported state of health using a visual analog scale (r = .33, p < .001), and it was negatively correlated with anxiety (r = -.22, p < .001) and depression (r = -.31, p < .001) (Patient Health Questionnaire; Loewe et al., 2004). The pessimism subscale was positively correlated with anxiety (r = 0.19, p < .001) and depression (r = .13, p
< .001), and negatively correlated with life satisfaction (r = -.28, p < .001) and self-reported health (r = -.18, p < .001).

**Beck Depression Inventory (BDI-II; Beck, Steer, & Brown, 1996).** The BDI-II is a commonly used screening instrument for depression. The self-report measure includes 21 items rated on a 4-point Likert scale ranging from 0 to 3. Respondents are instructed to choose statements characterizing how they have felt over the past two weeks. Item responses are summed for a total score and classified within a severity range (0 – 13 = minimal depression, 14 – 19 = mild depression, 20 – 28 = moderate depression, 29 – 63 = severe depression) (Beck et al., 1996). The BDI-II has been used in a variety of PD research (e.g., Ehman et al., 1990; Levin et al., 1988; Schrag et al., 2000), is considered a valid screening tool for depression in a PD population (Williams et al., 2012), and has been validated specifically for use with older adults (Segal, Coolidge, Cahill, & O’Riley, 2008; Steer, Rissmiller, & Beck, 2000). The BDI-II is also the preferred depression measure at the VCU PMDC versus other measures that might be appropriate for an older disease population (e.g., the Geriatric Depression Scale) due to the wider PD population age range and for the purposes of future comparison data within the PMDC.

In a study of psychometric properties of the BDI-II with community-dwelling adults (n = 376), the scale had adequate internal consistency reliability (α = .90) and item-total correlations (r = .25 - .64) (Segal et al., 2008). When the sample was divided into older adults (n = 157; M age = 70.3 years; age range 55-90 years) and younger adults (n = 229; M age = 19.6 years; age range 17-29 years), internal consistency reliability remained acceptable for the two samples (α = .86 and .92, respectively). Among older adults, the BDI-II correlated significantly and positively correlated with the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977) (r = .69, p < .001) and the depression subscale of Coolidge Axis II Inventory
(CATI; Coolidge & Merwin, 1992) \( r = .66, p < .001 \), which supported convergent validity. Regarding discriminant validity, the BDI-II scores for the older adults were significantly and negatively correlated with Short Psychological Well-Being Scale total score (SPWB; Ryff, 1989) \( r = -.60, p < .001 \) and six SPWB subscales \( r = -.31 \) to \( -.64, p < .001 \). Construct validity was established using a Principal Components Analysis, with a one-component solution accounting for 30% of the variance and all 21 items loading above a set criterion of .40.

**Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen, & Griffith, 1985)**. The SWLS is a brief instrument used to assess an individual’s life satisfaction. The self-report measure includes 5 items rated on a 7-point Likert scale. Individuals rate from 1 to 7 the degree to which they agree or disagree with a given statement. Scores are summed and can range from 5 to 35, with higher scores indicating greater life satisfaction.

The SWLS has adequate psychometric properties. In the initial validation study, the scale had acceptable two-month test-retest correlation \( r = .82 \) and internal consistency reliability \( \alpha = .87 \) (Diener et al., 1985). The SWLS also had convergent and discriminant validity, positively correlating with the well-being subscale of the Differential Personality Questionnaire \( r = .68 \) and the positive affect subscale of the Affect Balance Scale \( r = .50 \), and negatively correlating with the negative affect subscale of the Affect Balance Scale \( r = - .37 \). It also did not correlate significantly with the Marlowe-Crowne social desirability scale, demonstrating discriminant validity. The SWLS is recommended as a compliment to emotional well-being scales because it assesses an individual’s judgments of his or her own life according to his or her criteria (Pavot & Diener, 1993).

**Statistical analyses**
Statistical analyses were completed using SPSS Statistics 22 software. Statistical assumptions within the data set were checked, including missing data, required sample size, outliers, and univariate and multivariate normality. Regarding survey attrition rates and data cleaning, a total of 224 surveys were initiated during the April 2013 and October 2013 data collection period. Of these, 62.5% (n = 140) met criteria for use in the final data set. The remaining 37.5% (n = 84) were unable to be used for two main reasons: 1) initiated but incomplete survey with more than half of the data missing (n = 71), and 2) duplicates completed by same participant more than once (n = 13; in these instances, the earlier version of participant’s completed data was used to avoid response bias). There was 1 completed survey that was ultimately eliminated from the data set because the participant’s responses were outliers in several normality tests. This resulted with a final sample size of 139. Of the surveys that were eliminated and not used in the data set, the large majority of surveys initiated did not even have basic demographic data complete (i.e., survey was initiated but ended before any responses were entered). Only 15 participants initiated surveys and completed some demographic information, therefore these participants were compared to the final usable sample as seen in the table below. The participants that had incomplete surveys and were not included in the final sample were not significantly different in terms of demographic data compared to those who completed the entire survey.

Throughout the data collection process, any participants who submitted online or paper surveys with missing items were contacted via phone, and missing item responses were completed over the phone. Only three participants were unable to be reached because their phone number was no longer working, however these participants had minimal missing data (one participant had five missing items, one participant had four missing items, one participant had
one missing item). Missing data were analyzed using Little’s (1998) MCAR test; nonsignificant results indicated that the missing items were missing at random across all scale items, with 0.7% as the maximum percentage of missing data for any item ($\chi^2(182) = 11.63, p = 1.0$). Missing values were replaced using the Expectation-Maximization (EM) method, which is a recommended method for missing data within a multivariate model because it produces a nearly unbiased estimate of means and variances (Schafer & Olsen, 1998). The procedure involves SPSS and first estimates the parameters, then estimates the missing values, then fills in the data set to re-estimate the parameters, then uses the re-estimated parameters to estimate missing values, and so on until the process converges on stable estimates.

Univariate normality and outliers were checked for all variables of interest by using skewness and kurtosis cut-off values of +/- 1 and by analyzing converted z-score values to identify outliers. One participant was eliminated from the dataset based on scores on multiple measures that were outliers, as well as a self-reported comorbid diagnosis of schizophrenia. Other univariate outlier scores were windsorized to achieve normality, or assigning a raw score to the non-normal variable that is one unit larger (or smaller) than the next most extreme score in the distribution (Tabachnick & Fidell, 2001). The functional impairment measure was highly negatively skewed and kurtotic, with most participants reported relatively high functioning. After a reverse score transformation, which is indicated in negatively skewed data (Field, 2009), and a log transformation, the functional impairment variable achieved normal distribution with no outliers. As a result, although the functional impairment measure typically has higher scores indicating better functioning, the reverse score transformation changes the interpretation of results such that higher scores indicate poorer outcomes.
Throughout multiple regression analyses, all assumptions were met as well, including multivariate normality, linearity, homoscedasticity, and multicollinearity as analyzed through residual plots, Mahalanobis distance analyses, and tolerance and VIF scores (cut-offs of greater than 0.1 or less than 10, respectively, indicating no multicollinearity). During preliminary analyses and multiple regression analyses, there were several multivariate outliers (determined by Mahalanobis distance). Though these cases were statistical outliers, they appeared to be outliers only based on their demographic characteristics; the outliers were either ethnic minorities or they had unusual early onset PD (diagnosed during their 30’s). When these cases were eliminated from analyses, there were no multivariate outliers based on IV and DV scores of interest, confirming that these cases were outliers based solely on demographic characteristics. Therefore, these cases were included in analyses in order to maximize degrees of freedom and statistical power. Lastly, bivariate Pearson correlations among the target variables, with all cases included within the study, indicated that no two variables correlated above .76 (see Table 2).

All scales were administered in their entirety in the initial administration of the assessment in order to retain psychometric properties (Kazdin, 2010b), however potential subject fatigue was assessed to determine whether the survey should be shortened to only include subscales that reflect variables of interest. If participants did not complete the survey in its entirety, the most common pattern was for participants to cease completion during the demographic section or during the first questionnaire; the vast majority of participants completed the entire survey. Therefore, the decision was made to keep all scales and subscales in the survey because the length did not seem to be a barrier to survey completion. As previously mentioned, although all scales were completed, the Meaningfulness subscale (meaning-making ability, SOC-
Flexible Goal Adjustment subscale (goal-flexibility, TENFLEX), and optimism subscale (positivity, LOT-R) scores were separated from the parent scale scores and included in analyses. Additionally, the NMSQuest was administered in its entirety for the purposes of gathering comprehensive useful data for the VCU PMDC, however the items that targeted neuropsychiatric symptoms (i.e., apathy/attention/memory, hallucinations/delusions, depression/anxiety/anhedonia) were excluded from analyses, given that these symptoms correlated strongly with the mental health outcome variables. Furthermore, the PDQ-39 was administered in its entirety but assessed using different subscales in the analyses. The subscales that reflected disease symptoms (mobility, activities of daily living, and bodily discomfort) were summed and averaged to create a composite variable termed disease symptom-related QOL. The subscales that reflect disease adjustment (emotional well-being, stigma, social support, cognitions, communication) were summed and averaged to create a composite variable termed adjustment-related QOL. Lastly, in each regression equation, the following control variables were entered: age, sex, ethnicity, years of education, income level, and disease duration (as measured by years since diagnosis).
Table 2.

**Bivariate correlations of outcome variables**

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<tr>
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<th>1</th>
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<th>10</th>
<th>11</th>
</tr>
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<tbody>
<tr>
<td><strong>1</strong> Depression&lt;sup&gt;1&lt;/sup&gt;</td>
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<tr>
<td><strong>2</strong> Apathy&lt;sup&gt;1&lt;/sup&gt;</td>
<td>-----</td>
<td>.64**</td>
<td>-----</td>
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<tr>
<td><strong>3</strong> Life satisfaction</td>
<td>-.53**</td>
<td>-.36**</td>
<td>-----</td>
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<tr>
<td><strong>4</strong> Adjustment-related quality of life&lt;sup&gt;1&lt;/sup&gt;</td>
<td>-----</td>
<td>.76**</td>
<td>.50**</td>
<td>-.57**</td>
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<tr>
<td><strong>5</strong> Nonmotor symptoms&lt;sup&gt;1,2&lt;/sup&gt;</td>
<td>.32**</td>
<td>.22*</td>
<td>-.15</td>
<td>.41**</td>
<td>-----</td>
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<tr>
<td><strong>6</strong> Disease symptom-related quality of life&lt;sup&gt;1&lt;/sup&gt;</td>
<td>.51**</td>
<td>.33**</td>
<td>-.34**</td>
<td>.68**</td>
<td>.51**</td>
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<tr>
<td><strong>7</strong> Functional impairment&lt;sup&gt;1&lt;/sup&gt;</td>
<td>.35**</td>
<td>.37**</td>
<td>-.36**</td>
<td>.57**</td>
<td>.39**</td>
<td>.63**</td>
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<tr>
<td><strong>8</strong> Resilience</td>
<td>-.63**</td>
<td>-.57**</td>
<td>.66**</td>
<td>-.62**</td>
<td>-.18*</td>
<td>-.30**</td>
<td>-.31**</td>
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<tr>
<td><strong>9</strong> Meaning-making ability</td>
<td>-.62**</td>
<td>-.58**</td>
<td>.50**</td>
<td>-.53**</td>
<td>-.18*</td>
<td>-.33**</td>
<td>-.26**</td>
<td>.71**</td>
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<tr>
<td><strong>10</strong> Goal-flexibility</td>
<td>-.49**</td>
<td>-.33**</td>
<td>.45**</td>
<td>-.49**</td>
<td>-.24**</td>
<td>-.29**</td>
<td>-.29**</td>
<td>.55**</td>
<td>.50**</td>
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</tr>
<tr>
<td><strong>11</strong> Optimism</td>
<td>-.51**</td>
<td>-.41**</td>
<td>.52**</td>
<td>-.53**</td>
<td>-.09</td>
<td>-.27**</td>
<td>-.27**</td>
<td>.63**</td>
<td>.56**</td>
<td>.48**</td>
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</tr>
</tbody>
</table>

<sup>1</sup> Higher scores indicate poorer outcomes.

<sup>2</sup> Seven items from this scale were excluded from analyses and total score calculation due to conceptual similarities to mental health/QOL outcome variables (i.e., nonmotor neuropsychiatric symptoms).

* *p< .05

** *p<.001
Results

Demographic and Clinical Characteristics

The demographic characteristics of the 139 participants are listed in Table 3. The participants in the study were in their mid-sixties ($M = 64.25$, $SD = 10.12$, age range 34-89 years), slight majority female (54%) and retired (54.4%), mostly Caucasian (95%), and well-educated (65.9% had Bachelor’s degree or higher). Participants reported first noticing PD symptoms an average of 3.28 years ago ($SD = .99$, range 1-5 years ago), received a PD diagnosis 6.39 years ago ($SD = 5.02$, range 1-32 years), with 44.9% reporting their disease progression as stable. A majority of participants reported no comorbid diagnoses other than PD (58.3%). For the few participants that did not report their PD diagnosis year, their reported number of years since they first noticed symptoms was substituted instead in analyses.

The mean score for the BDI-II was 12.1 ($SD = 7.79$), with 35% reporting clinically significant levels of depression (score $\geq 14$). Based on the BDI-II manual’s score interpretation guidelines (Beck et al., 1996), 18.7% of study participants had mild depression, 12.9% had moderate depression, and 3.5% had severe depression. This depression frequency is greater than another sample of non-demented PD patients (Kirsch-Darrow, Marsiske, Okun, Bauer, & Bowers, 2011) in which one quarter of the sample had clinically significant depressive symptoms. The mean score for the SAS was 12.22 ($SD = 6.18$), with 46% of study participants scoring above the clinical cut-off for apathy (Starkstein et al., 1992). This apathy frequency is higher than the Kirsch-Darrow and colleagues (2011) PD sample, in which 33.5% of participants had clinically significant levels of apathy (score $\geq 14$). The present study’s average apathy score is lower, however, compared to another sample of early untreated PD patients ($M = 15.5$, $SD = 4.6$) (Pedersen et al., 2012). Additional analyses compared mental health prevalence rates to
other studies that looked at concomitant apathy and depression (e.g., Benito-Leon, Cubo, & Coronell, 2012). In the present study, 17.3% had clinically significant apathy alone (n = 24), 6.5% had clinically significant depression alone (n = 9), 28.8% had comorbid apathy and depression (n = 40), and 47.5% had neither depression nor apathy (n = 66). These rates are similar to those reported in the Benito-Leon et al. study (22% apathy alone, 14% depression alone, 30% comorbid apathy and depression).

Regarding life satisfaction, the mean score for study participants was 23.46 (SD = 7.06), which is within the average life satisfaction score range (Diener et al., 1985) and similar to life satisfaction reported in other PD samples (Lucas-Carrasco, Den Oudsten, Eser, & Power, 2014). As previously mentioned, the average scores for adjustment-related quality of life and disease symptom-related quality of life represent composite scores from combinations of the Parkinson’s Disease Questionnaire-39 subscales (Jenkinson et al., 2008). While these composite scores are meaningful within the context of this project for the purposes of differentiating between adjustment-related QOL (emotional well-being, stigma, social support, cognitions, communication) and disease symptom-related QOL (mobility, activities of daily living, and bodily discomfort), there are no other studies to this writer’s knowledge that have created these composites. Therefore, the PDQ-39 Single Index (SI) score was used to compare to other normative samples. According to the PDQ-39 manual (Jenkinson et al., 2008), the PDQ-39 SI is a meaningful alternative to the eight scales of the PDQ-39 and is calculated by summing and averaging the scores from the eight dimensions. Participant’s average SI score in the present study was 24.83 (SD = 13.54), which is slightly lower than the normative sample scores reported in the PDQ-39 manual (Jenkinson et al., 2008), indicating slightly better QOL and less negative impact of PD on participants’ daily lives.
Participants reported an average of 11.76 nonmotor symptoms (total NMS score) \( (SD = 4.90; \text{median} = 11.5, \text{mode} = 15, \text{range } 1-23) \). These NMS scores are similar to those that have been previously reported with other PD populations (Chaudhuri et al., 2006). Although the functional impairment (FIM) variable was highly negatively skewed and required transformation prior to multiple linear regression analyses, participants’ scores on the FIM were comparable to other PD studies (Muslimovic et al., 2008). The average score on the FIM was 121.60 \( (SD = 7.19) \), with most participants reporting high ADL independence (scale maximum score = 126).

Study participants’ average score on the RSA was 126.99 \( (SD = 17.45) \), which is very similar to a large normative sample of adults (Friborg et al., 2009) and a high-risk group of young women (Jowkar, Friborg, & Hjemdal, 2010). Of note, while there was a normal distribution of scores on this scale, the cluster of scores was toward the higher end of the scale. RSA scores can range from 33 to 165, however the range in the present study was from 75 to 163. Considering the average total score of 126.99 another way, the average response on a given item was 3.85 (33 items, 5-point scale), with the large majority of participants reporting high resilience across items. By using the 3 value on the scale as a midpoint, only 6% of participants reported average resilience scores below the midpoint and 94% rated themselves at or above the midpoint across items.

Meaning-making ability was assessed using the meaningfulness subscale of the SOC (Antonovsky, 1993), and the average score was 21.80 \( (SD = 4.5) \). Because other studies with PD patients used the entire SOC scale (comprehensibility, manageability, and meaningfulness components), the average total SOC score is reported in Table 3 for comparison purposes. Study participants scored slightly higher on total SOC \( (M = 67.91, SD = 12.96) \) compared to other studies of PD patients (Caap-Ahlgren & Dehlin, 2003) and similar to a study of community-
dwelling older adults (Gurina, Frolova, & Degryse, 2011). Goal-flexibility was measured using the flexible goal adjustment subscale (FGA) of the TENFLEX (Brandtstädter & Renner, 1990). The mean score on the FGA was 37.41 ($SD = 6.98$), which is comparable to other FGA scores reported in samples of spinal cord injury patients (van Lankveld, van Diemen, & van Nes, 2011) and middle-aged and older patients recruited from a community-based rehabilitation agency (Boerner, 2004). Lastly, optimism was assessed using the LOT-R optimism subscale (Scheier et al., 1994), with a mean score of 8.59 ($SD = 2.68$). These scores are similar to average optimism subscale scores in a large population-based sample ($M = 8.5, SD = 2.3$) (Glaesmer et al., 2012) and slightly higher than optimism scores from PD patients at a university-affiliated Parkinson’s Disease and Movement Disorders Center ($M = 7.7, SD = 2.5$) (Robottom et al., 2012).

Table 3.

<table>
<thead>
<tr>
<th>Mean Scores on Demographic and Study Variables</th>
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<tbody>
<tr>
<td><strong>Demographic variables</strong></td>
</tr>
<tr>
<td>Age</td>
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<tr>
<td>Sex (% Female)</td>
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<tr>
<td>Ethnicity (% Caucasian)</td>
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<tr>
<td>Education (% Bachelor’s degree or higher)</td>
</tr>
<tr>
<td>Employment (% Retired)</td>
</tr>
<tr>
<td>Yearly income ($)</td>
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<tr>
<td>Years since PD diagnosis</td>
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<tr>
<td>Self-reported depression history (% yes)</td>
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<tr>
<td><strong>Study variables</strong></td>
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<tr>
<td><strong>Outcome variables</strong></td>
</tr>
<tr>
<td>Depression</td>
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<tr>
<td>Apathy</td>
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<tr>
<td>Life satisfaction</td>
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<tr>
<td>Adjustment-related quality of life</td>
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<tr>
<td><strong>Predictor variables</strong></td>
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<tr>
<td>Nonmotor symptoms(^1)</td>
</tr>
<tr>
<td>Disease symptom-related quality of life</td>
</tr>
<tr>
<td>Functional impairment(^2)</td>
</tr>
<tr>
<td>Variable</td>
</tr>
<tr>
<td>------------------------</td>
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<tr>
<td>Resilience</td>
</tr>
<tr>
<td>Meaning-making ability</td>
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<tr>
<td>Goal-flexibility</td>
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<tr>
<td>Optimism</td>
</tr>
</tbody>
</table>

*Note. Measures used to assess these variables listed in Method section.*

1. The total scores for the Nonmotor Symptoms Questionnaire (NMSQuest) are reported here, however several items from the scale were excluded in analyses due to conceptual overlap with mental health/QOL outcome variables (i.e., nonmotor neuropsychiatric symptoms). The correlation values presented in Table 2 reflect the NMS Total score with items excluded.

2. The raw scores of the functional impairment measure (FIM-SR) are reported here. However, as previously noted in the statistical analyses section, the scores were reverse scored and a log transformation was performed such that the variable achieved normality and met assumptions for multiple regression analyses. This reverse score transformation switches the direction of interpretation of functional impairment scores; with the raw variable, higher scores indicated better functioning, but with the transformed variable, higher scores indicate poorer functioning.

**Regression Analyses**

Table 3 presents the means and standard deviations for the variables of interest, and Tables 4-7 depict the beta weights, incremental changes in $R^2$ with each model, and corresponding $F$ values for the final models. For each dependent variable, the control variables and main predictor variables (nonmotor symptoms, functional impairment, and disease symptom-related quality of life) were entered into multiple linear regression models. Hierarchical multiple regression analyses were used to test the moderating effects of resilience and hypothesized age-related resilience variables. One advantage to hierarchical multiple regression is that variables are entered into the model in theoretically-specified order, which allows each variable to be evaluated based on its predictive value after earlier-entry variables account for other variance. This *a priori* assumption about variable entry order is theory-driven and appropriate for the present study given the conceptual exploration of late life resilience.

**Main outcome variables.**
**Depression.** The regression model significantly predicted BDI-II scores and explained 32.6% of the variance in depression, \( F(9,123) = 6.61, p < .001, R^2 = .33 \) (Table 4). Significant predictors of depression included age (\( \beta = -.17, t(123) = -2.19, p = .031 \)) and disease symptom-related QOL (\( \beta = .38, t(123) = 3.55, p = .001 \)). The other hypothesized predictor variables, nonmotor symptoms and functional impairment, were not significant predictors (\( \beta = .10, t(123) = 1.13, p = .259; \beta = .08, t(123) = 0.82, p = .413 \), respectively).

**Apathy.** The regression model significantly predicted Starkstein Apathy Scale scores and explained 20.9% of the variance in apathy, \( F(9,123) = 3.62, p < .001, R^2 = .21 \) (Table 5). The only significant predictor of apathy was functional impairment (\( \beta = .28, t(123) = 2.58, p = .011 \)). As functional impairment scores increased (indicating less ADL independence), apathy also increased. The other hypothesized predictor variables, nonmotor symptoms and disease symptom-related QOL, were not significant predictors (\( \beta = .08, t(123) = 0.84, p = .402; \beta = .10, t(123) = 0.86, p = .391 \), respectively).

**Life satisfaction.** The regression model significantly predicted Satisfaction With Life Scale scores and explained 25.7% of the variance in life satisfaction, \( F(9,123) = 4.73, p < .001, R^2 = .26 \) (Table 6). The significant predictors of life satisfaction were income (\( \beta = .31, t(123) = 3.44, p = .001 \)) and functional impairment (\( \beta = -.23, t(123) = -2.22, p = .028 \)). As functional impairment scores increased (indicating less ADL independence), life satisfaction decreased. The other hypothesized predictor variables, nonmotor symptoms and disease symptom QOL, were not significant predictors (\( \beta = .05, t(123) = .58, p = .566; \beta = -.14, t(123) = -1.29, p = .199 \), respectively).

**Adjustment-related quality of life.** The regression model significantly predicted adjustment-related QOL scores and explained 58.3% of the variance in adjustment-related QOL,
$F(9,123) = 19.12, p < .001, R^2 = .58$ (Table 7). The significant predictors of adjustment-related QOL were age ($\beta = -.30, t(123) = -4.92, p < .001$), income ($\beta = -.16, t(123) = -2.40, p = .018$), disease symptom-related QOL ($\beta = .43, t(123) = 5.12, p < .001$), and functional impairment ($\beta = .27, t(123) = 3.47, p = .001$). Poorer disease symptom QOL and lower ADL independence were associated with worse adjustment-related QOL. The nonmotor symptoms variable was not a significant predictor ($\beta = .08, t(123) = 1.17, p = .245$).

**Resilience as a moderator.** For each of the previous main analyses, the resilience variable was entered into the models in Block 2 to test Hypothesis 2 whether resilience moderates the relationship between the significant predictor and outcome variables. Given that there was a main effect of disease symptom-related QOL on depression, resilience was entered into the model as a moderator variable. There was a significant main effect of resilience on depression ($\beta = -.51, t(124) = -7.62, p < .001$) such that as resilience increases, depression decreases. Resilience uniquely accounted for an additional 21.9% of the variance in depression above and beyond age, income, and disease symptom-related QOL. The interaction term, however, was not significant, and the effect of disease symptom-related QOL on depression did not depend on resilience ($\beta = .04, t(123) = .54, p = .592$).

Resilience was entered as a moderator variable into the model with functional impairment predicting apathy. There was a significant main effect of resilience on apathy ($\beta = -.48, t(124) = -6.09, p < .001$) such that as resilience increases, apathy decreases. Resilience uniquely accounted for an additional 18.5% of the variance in apathy above and beyond functional impairment. The interaction term, however, was not significant, and the effect of functional impairment on apathy did not depend on resilience ($\beta = .01, t(123) = .10, p = .919$).
Resilience was also a significant predictor of life satisfaction, ($\beta = .56, t(124) = 8.05$, $p < .001$), with higher resilience scores associated with higher life satisfaction. Resilience uniquely accounted for 25.8% of additional variance in life satisfaction above and beyond functional impairment. The effect of functional impairment on life satisfaction, however, did not depend on resilience ($\beta = -.01, t(123) = -.18$, $p = .856$).

Lastly, resilience was a significant predictor of adjustment-related QOL, ($\beta = -.44, t(123) = -8.47$, $p < .001$) and uniquely accounted for an additional 15.5% of the variance above and beyond age, income, functional impairment, and disease symptom-related QOL. Higher resilience scores were associated with better adjustment-related QOL. Resilience was not a significant moderator, however, of the relationship between adjustment-related QOL and disease symptom-related QOL ($\beta = .03, t(121) = .56, p = .574$) nor the relationship between adjustment-related QOL and functional impairment ($\beta = -.05, t(121) = -.86, p = .392$). While both functional impairment and disease symptom-related QOL were significant predictors of adjustment-related QOL, neither was affected by resilience. Education also emerged as a significant predictor, such that those with greater education had better adjustment-related QOL ($\beta = .12, t(121) = 2.34, p = .021$).

**Hypothesized resilience-related variables.** Although the resilience variable was not a significant moderator between disease-related symptoms (nonmotor symptoms, functional impairment, disease symptom-related QOL) and mental health/QOL (depression, apathy, life satisfaction, adjustment-related QOL), resilience and other hypothesized resilience variables were highly correlated with several outcome variables (Table 2). Therefore, hierarchical multiple regression analyses were conducted with resilience entered into Block 2 and the hypothesized age-related resilience variables (meaning-making ability, goal-flexibility, and optimism) entered
into Block 3. All previously entered control variables from the initial analyses were included in these models, however nonsignificant predictor variables were dropped from analyses to generate the most parsimonious model with the highest available degrees of freedom for other variables. Finally, a set of models for each outcome variable was run with all significant predictor variables, the resilience variable, and all hypothesized resilience variables entered simultaneously. Results of these models are reported only for instances in which a previously nonsignificant hypothesized resilience variable became significant (i.e., the resilience variable entered in Block 2 was obscuring the effects of the hypothesized resilience variable in Block 3).

Regarding depression, the 3rd model with the hypothesized age-related resilience variables accounted for the highest proportion of variance ($R^2 = .57$) and was significantly better than the previous models, $\Delta F(3,121) = 3.74, p = .013$. This improved model was solely driven by the addition of the meaning-making ability variable. After including control variables, disease symptom-related QOL, and resilience, meaning-making ability significantly predicted depression and uniquely accounted for an additional 2.1% of the variance ($\beta = -.22, t(121) = -2.49, p = .014$). Goal-flexibility and optimism did not significantly predict depression ($\beta = -.09, t(121) = -1.21, p = .229; \beta = -.06, t(121) = -.71, p = .476$, respectively). This pattern of significance did not differ when all variables were entered simultaneously, with disease-symptom related QOL, resilience, as meaning-making ability as the only significant variables.

Similarly for apathy, the 3rd model with the hypothesized age-related resilience variables accounted for the highest proportion of variance ($R^2 = .45$) and was significantly better than the previous models, $\Delta F(3,121) = 4.77, p = .004$. This improved model was again driven primarily by the meaning-making ability variable. After including control variables, functional impairment, and resilience, meaning-making ability significantly predicted apathy and accounted
for 6.4% of additional variance ($\beta = -.38, t(121) = -3.73, p < .001$). Goal-flexibility and optimism did not significantly predict apathy ($\beta = .04, t(121) = .666, p = .68; \beta = .01, t(121) = .12, p = .904$, respectively). This pattern of significance did not differ when all variables were entered simultaneously, with functional impairment, resilience, as meaning-making ability as the only significant variables. Meaning-making ability actually became a stronger predictor ($\beta = -.38, t(121) = -3.73, p < .001$) than resilience ($\beta = -.25, t(121) = -2.24, p = .027$) and functional impairment ($\beta = .23, t(121) = 2.90, p = .004$) when entered at the same step and given an equal chance at accounting for variance in apathy.

The 3rd model with the hypothesized age-related resilience variables also accounted for the most variance in life satisfaction ($R^2 = .54$) and was significantly better than previous models, $\Delta F(3,121) = 2.90, p = .038$. Goal flexibility was the only significant additional variable in the final model ($\beta = .17, t(121) = 2.14, p = .034$). Neither meaning-making ability ($\beta = -.06, t(121) = -.61, p = .542$) nor optimism ($\beta = .14, t(121) = 1.64, p = .104$) were significant predictors of life satisfaction. This pattern of significance differed slightly when all variables were entered simultaneously, with functional impairment becoming non-significant ($\beta = -.10, t(121) = -1.39, p = .167$). Sex was also a significant predictor in this final model ($\beta = .13, t(121) = 2.12, p = .036$), with female sex associated with greater life satisfaction.

Regarding adjustment-related QOL, the 3rd model with the hypothesized age-related resilience variables accounted for the most variance ($R^2 = .75$) but was not significantly better than previous models, $\Delta F(3,120) = 2.31, p = .08$. None of the hypothesized age-related resilience variables were significant predictors; neither meaning-making ability, goal-flexibility, nor optimism significantly predicted adjustment-related QOL ($\beta = .03, t(120) = .48, p = .631; \beta = -.09, t(120) = -1.45, p = .149; \beta = -.12, t(120) = -1.92, p = .058$, respectively). This pattern of
significance did not differ when all variables were entered simultaneously, with age, education, disease symptom-related QOL, functional impairment, and resilience as the only significant variables.

Given the exploratory nature of this project in understanding the relationships among coping and resilience variables in an older, chronic disease population, a post-hoc mediation analysis was completed. There is good theoretical support for a relationship between meaning-making ability and optimism as key features of Fredrickson’s (1998) broaden-and-build model of coping, therefore optimism was tested as a mediator of the relationship between meaning-making ability and depression. Using the Baron and Kenny (1986) method for testing mediation, a significant relation between meaning-making ability and depression was first established, \( F(1,137) = 85.89, p < .001; R^2 = .39, \beta = -.62 \). Next, meaning-making ability was found to have a significant effect on optimism \( F(1,137) = 62.96, p < .001; R^2 = .32, \beta = .56 \). After controlling for meaning-making ability, participants who had greater optimism had less depression than those with less optimism \( F(2,136) = 49.44, p < .001; R^2 = .42, \beta = -.23 \). Using the Sobel test, it was found that the magnitude of the relationship between meaning-making ability and depression decreased significantly when optimism was included \( (z = -2.74, p = .007) \). Therefore, optimism partially mediated the effect of meaning-making ability on depression. When the same analyses were run with optimism mediating the relationship between meaning-making ability and apathy, optimism was not a significant mediator \( (\beta = -.13, t(136) = -1.54, p = .126) \).
# Table 4.
## Summary of Hierarchical Regression Analysis for Variables Predicting Depression

<table>
<thead>
<tr>
<th>Variable</th>
<th>Model 1</th>
<th></th>
<th></th>
<th>Model 2</th>
<th></th>
<th></th>
<th>Model 3</th>
<th></th>
<th></th>
</tr>
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<tbody>
<tr>
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<td>SE</td>
<td>p-value</td>
<td>( \beta )</td>
<td>SE</td>
<td>p-value</td>
<td>( \beta )</td>
<td>SE</td>
<td>p-value</td>
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<td>.058</td>
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<td>.000***</td>
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<td>0.03</td>
<td>.000***</td>
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<td>.592</td>
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<td>.573</td>
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*Note. Ethnicity was dichotomously coded (1 = Non-Caucasian, 2 = Caucasian).*

*p < .05.  **p < .01.  ***p < .001
Table 5.
Summary of Hierarchical Regression Analysis for Variables Predicting Apathy

<table>
<thead>
<tr>
<th>Variable</th>
<th>Model 1</th>
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<th>Model 3</th>
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<td>$p$-value</td>
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<td>Income</td>
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<td>.131</td>
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<td>.576</td>
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<tr>
<td>Disease symptom-related QOL</td>
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<tr>
<td>Nonmotor symptoms</td>
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<td>0.15</td>
<td>.402</td>
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<tr>
<td>Functional impairment</td>
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<tr>
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<td>.000***</td>
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<td>Goal-flexibility</td>
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<tr>
<td>Optimism</td>
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</table>

*Note. Ethnicity was dichotomously coded (1 = Non-Caucasian, 2 = Caucasian).  

*p < .05. **p < .01. ***p < .001
Table 6.  
Summary of Hierarchical Regression Analysis for Variables Predicting Life Satisfaction

<table>
<thead>
<tr>
<th>Variable</th>
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<td>Sex</td>
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<td>.075</td>
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<td>Disease symptom-related QOL</td>
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<td>Nonmotor symptoms</td>
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<td>.566</td>
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<td>Functional impairment</td>
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*Note. Ethnicity was dichotomously coded (1 = Non-Caucasian, 2 = Caucasian).

*p < .05.  **p < .01.  ***p < .001
Table 7.  
*Summary of Hierarchical Regression Analysis for Variables Predicting Adjustment-related QOL*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Model 1</th>
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<th>Model 2</th>
<th></th>
<th>Model 3</th>
<th></th>
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<td>SE</td>
<td>p-value</td>
<td>β</td>
<td>SE</td>
<td>p-value</td>
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<td>-.25</td>
<td>0.06</td>
<td><strong>.000</strong>*</td>
</tr>
<tr>
<td>Sex</td>
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<td>-.04</td>
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<td>.146</td>
<td>.12</td>
<td>0.40</td>
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<tr>
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<td><strong>.000</strong>*</td>
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<td>0.05</td>
<td><strong>.000</strong>*</td>
</tr>
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<td>Nonmotor symptoms</td>
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</tr>
<tr>
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<td><strong>.000</strong>*</td>
<td>.17</td>
<td>1.82</td>
<td><strong>.011</strong>*</td>
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<td>0.06</td>
<td><strong>.000</strong>*</td>
</tr>
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*Note. Ethnicity was dichotomously coded (1 = Non-Caucasian, 2 = Caucasian).  
*p < .05. **p < .01. ***p < .001*
**Depression subtypes.** Exploratory analyses with depression subtypes were conducted to determine whether any variables of interest differentially affected the cognitive versus somatic symptoms of depression (Dozois, Dobson, & Ahnberg, 1998). BDI-II scores were calculated with items split into Cognitive-Affective and Somatic-Vegetative subscales (e.g., items assessing self-dislike, worthlessness, guilty feelings, and sadness in the former subscale; items assessing fatigue, irritability, agitation in the latter subscale). The same multivariate regression model steps were run as were completed for the total BDI-II score.

For the Cognitive-Affective Depression subscale with control variables and main predictors included, the model was significant and explained 26.2% of the variance in cognitive-affective depressive symptoms, $F(9,123) = 4.86, p < .001$. Significant predictors included age ($\beta = -.21, t(123) = -2.60, p = .01$) and disease symptom-related QOL ($\beta = .28, t(123) = 2.52, p = .013$). The other hypothesized predictor variables, nonmotor symptoms and functional impairment, were not significant predictors ($\beta = .03, t(123) = 0.36, p = .718; \beta = .13, t(123) = 1.27, p = .208$, respectively). When resilience was added as a moderator, there was a significant main effect of resilience on cognitive-affective depression ($\beta = -.61, t(124) = -9.35, p < .001$) such that as resilience increases, depression decreases. Resilience uniquely accounted for an additional 30.9% of the variance in depression above and beyond age and disease symptom QOL. The interaction term, however, was not significant, and the effect of disease symptom QOL on cognitive-affective depression did not depend on resilience, $\beta = .02, t(123) = 0.32, p = .751$.

The model improved further with the hypothesized age-related resilience variables included. This final model accounted for the highest proportion of variance ($R^2 = .60$) and was significantly better than the previous models, $\Delta F(3,121) = 4.33, p = .006$. This improved model
was driven by the goal flexibility variable. Although goal flexibility did not account for unique variance above and beyond resilience as a predictor for total depression, it did significantly predict cognitive-affective depression symptoms and uniquely accounted for an additional 1.6% of the variance ($\beta = -.17, t(121) = -2.26, p = .026$). Neither meaning-making ability nor optimism significantly predicted cognitive-affective depression ($\beta = -.17, t(121) = -1.94, p = .055; \beta = -.05, t(121) = -0.62, p = .539$, respectively).

For the Somatic-Vegetative Depression subscale with control variables and main predictors included, the model was significant and explained 32.5% of the variance in somatic-vegetative depressive symptoms, $F(9,123) = 6.57, p <.001$. Disease symptom-related QOL was the only significant predictor in this model ($\beta = .42, t(123) = 3.98, p < .001$). The other hypothesized predictor variables, nonmotor symptoms and functional impairment, were not significant ($\beta = .15, t(123) = 1.71, p = .090; \beta = .01, t(123) = .14, p = .888$, respectively).

Resilience was tested as a moderator for the relationship between disease symptom-related QOL and somatic-vegetative depression. There was a significant main effect of resilience on somatic-vegetative depression ($\beta = -.34, t(124) = -4.48, p <.001$) such that as resilience increases, depression decreases. Resilience uniquely accounted for an additional 9.6% of the variance in depression above and beyond income and disease symptom QOL. The interaction term, however, was not significant, and the effect of disease symptom QOL on somatic-vegetative depression did not depend on resilience ($\beta = .04, t(123) = .52, p = .605$).

Lastly, when the hypothesized age-related resilience variables were included in the last block, the model was not significantly better than previous models with disease symptom-related QOL and resilience predictor variables($\Delta F(3,121) = 2.42, p = .069$). This final model accounted
for the highest proportion of variance ($R^2 = .44$), however, primarily driven by the meaning-making ability variable as the only significant added predictor ($\beta = -.24, t(121) = -2.37\ p = .019$).

**Other moderation analyses.**

*Hypothesized resilience variables as moderators.* Given that resilience itself was not a significant moderator, however several hypothesized age-related resilience variables were significant predictors, further analyses were run to test whether these other resilience variables could moderate the relationship between main predictor and outcome variables. The variables were tested as potential moderators only for significant predictor variables in previous analyses.

Meaning-making ability did not significantly moderate the relationship between disease symptom-related QOL and total depressive symptoms ($\beta = .07, t(123) = .99, p = .323$) nor somatic-vegetative depression symptoms ($\beta = .08, t(123) = 1.01, p = .32$), such that the effect of disease symptom-related QOL on depression did not depend on meaning-making ability. Meaning-making ability also did not significantly moderate the relationship between functional impairment and apathy ($\beta = .01, t(123) = .16, p = .873$).

Goal-flexibility did not significantly moderate the relationship between disease symptom-related QOL and cognitive-affective depression symptoms ($\beta = -.06, t(123) = -.81, p = .420$). Although both disease symptom-related QOL and goal-flexibility were predictors of cognitive-affective depression symptoms, the effect of disease symptom-related QOL on depression did not depend on goal-flexibility. Similarly, goal-flexibility did not moderate the relationship between functional impairment and life satisfaction ($\beta = -.01, t(123) = -.15, p = .878$).

*Age as a moderator.* Age was also tested as a moderator between outcome variables and significant hypothesized age-related resilience variables. For example, as seen in Table 4, meaning-making ability was a significant predictor of depression. Therefore, an analysis was
conducted to determine whether age influenced the effect of meaning-making ability on depression. There was a significant main effect of meaning-making ability on depression ($\beta = -.59$, $t(126) = -8.31, p < .001$), such that as meaning-making ability increases, depression decreases. Meaning-making uniquely accounted for 32.6% of the variance in depression. The interaction term between age and meaning-making ability was also significant ($\beta = .17$, $t(124) = 2.32, p = .022$). For all participants, greater meaning-making ability was associated with lower depression, however this effect was greater for younger participants (Figure 2). There was also a significant moderating effect of age on the relationship between optimism and adjustment-related QOL ($\beta = .18$, $t(124) = 2.38, p = .019$). The effect of optimism on adjustment-related QOL was greater for younger participants (Figure 3). Age did not moderate the relationship between meaning-making ability and apathy ($\beta = .13$, $t(124) = 1.69, p = .093$) nor goal-flexibility and life satisfaction ($\beta = -.10$, $t(124) = -1.35, p = .179$).
Figure 2. Age as a moderator in the relationship between meaning-making ability and depression. The buffering effect of meaning-making ability on depression scores is greater for younger participants.
Figure 3. Age as a moderator in the relationship between optimism and adjustment-related QOL (higher scores = poorer outcomes).

The buffering effect of optimism on adjustment-related QOL is greater for younger participants.
**Moderated mediation.** Given that meaning-making ability appeared to be a key variable in several models, and the effect of age on these relationships was a primary goal of this study, exploratory analyses were conducted to determine if there were moderated mediation effects. A moderated mediation (conditional indirect effects) path model was constructed using AMOS 16.0 (Arbuckle, 2007) following Preacher, Rucker, and Hayes’ (2007) methodology. In the bootstrap model, resilience was specified to mediate the effect of meaning-making ability on depression. To examine whether the strength, direction, or presence of these hypothesized mediated effects differed by patient age, a median split of the sample created a younger (age range 34-64 years) and older group (age range 65-89 years). Models were run separately but simultaneously for the younger and older groups.

In Figure 4, for the younger group, the standardized indirect (mediated) effect was $\beta = -0.134$, $p = .156$, indicating that resilience did not mediate the path from meaning-making ability to depression for this group. For the older group, however, the standardized indirect effect was $\beta = -0.345$, $p = .001$, indicating the presence of statistical mediation. Because the direct effect of meaning-making ability on depression was not statistically significant while controlling for resilience, this is considered a full mediation. The combination of a full mediation for older participants and no mediation for the younger group indicates a moderated (by age group) mediation. To test whether the difference in indirect effects being moderated as a function of young vs. old was statistically significant, a heterogeneity test (Altman, 2003) was performed. This test suggested that the difference in indirect effects between the two groups was statistically
significant, $z = 2.85, p = .004$.

Note. ** = $p<.01$, *** = $p <.001$. Path coefficients in parentheses are from the younger group, and coefficients not in parentheses are from the older group.

Figure 4. Moderated mediation model: the influence of resilience on the relationship between meaning-making ability and depression, with age as moderating variable.

**Illness uncertainty.** Following the previous models based on primary hypotheses, additional exploratory variables were tested as possible predictors. Additional multiple regression analyses were run using the control variables and significant predictors from Model 3 in Tables 4-7, with the variable *illness uncertainty* included as an independent variable. Illness uncertainty accounted for 1.8% of unique variance as a significant predictor of depression ($\beta = .15, t(122) = 2.30, p = .023$). Participants who reported greater concern about the uncertainty of
their illness had higher depression scores. The final model including the previously significant predictors from Table 3 remained significant \( (F(10,122) = 17.03, p < .001, R^2 = .58) \). Illness uncertainty was also a significant predictor of life satisfaction \( (\beta = -0.20, t(122) = -3.01, p = .003) \) and accounted for 3.3% of unique variance. Greater concern about illness uncertainty was associated with lower life satisfaction. The final life satisfaction model remained significant with the illness uncertainty variable included \( (F(10,122) = 15.62, p < .001, R^2 = .56) \). Lastly, illness uncertainty significantly predicted adjustment-related QOL \( (\beta = .15, t(122) = 3.04, p = .003) \) and accounted for 1.9% of unique variance. The final adjustment-related QOL model remained significant \( (F(10,122) = 37.11, p < .001, R^2 = .75) \). The only outcome variable that illness uncertainty did not significantly predict was apathy \( (\beta = -.07, t(122) = -0.87, p = .336) \).

**Spirituality.** Spirituality, as measured through a composite variable of three spirituality items from the CD-RISC (Connor & Davidson, 2003), was also analyzed as an additional predictor variable into the final models from Tables 4-7. Spirituality was not a significant predictor of depression \( (\beta = .02, t(122) = 0.03, p = .976) \), life satisfaction \( (\beta = .09, t(122) = 1.33, p = .188) \), adjustment-related QOL \( (\beta = .01, t(122) = 0.21, p = .838) \), nor apathy \( (\beta = -.13, t(122) = -1.78, p = .078) \).

**Resilience subgroup comparisons.** Further analyses of the resilience variable were conducted given that resilience was a significant predictor in all main analyses and it was a primary variable of interest in this project. Additionally, the range of scores on the RSA was restricted to the upper end of the scale for the large majority of participants. Therefore, there were participants who reported moderate resilience characteristics yet also had clinically significant depression and apathy scores. There is some precedent for creating resilience subgroups based on median split scores (Friborg et al., 2006), however there are no guidelines
for cut-off scores on the RSA that are considered “high versus low” resilience. In the present study, participants were divided into low, medium, and high resilience groups based on percentile splits at the 33rd and 66th percentile in order to compare groups. There were 46 participants in the low resilience group (RSA range 75-120), 51 participants in the medium resilience group (RSA range 121-136), and 42 participants in the high resilience group (RSA range 137-163).

While using resilience scores as a continuous variable was a powerful predictor in regression analyses, it is helpful to determine whether there are differences between participants with relative differences between their resilience scores. Analysis of variance tests were conducted to compare scores on the outcome variables of interest between the three resilience groups. For variables in which there was a significant Levene’s statistic, indicating that the assumption of homogeneity of variance was violated, the test statistic and corresponding degrees of freedom reported were calculated with equal variances not assumed (Field, 2009). Table 8 shows the overall results comparing the three different resilience groups across the main outcome variables and the three main predictor variables (nonmotor symptoms, disease symptom-related QOL, and functional impairment). Planned contrasts were used to determine which groups differed significantly from each other.

As seen in Table 8, there were significant differences between the low, medium, and high resilience groups in an overall analysis of variance test, except for the overall group differences in nonmotor symptoms once a Bonferroni correction was applied. There was also a significant difference between the three groups for nearly all contrasts, meaning that the low, medium, and high resilience groups had significantly different scores on the outcome variables of interest. The low resilience group had significantly higher NMS scores (more nonmotor symptoms) compared to the medium resilience group ($t(136) = -2.50, p = .013$), but not the high resilience group
The low resilience group also had poorer disease symptom-related QOL compared to the high resilience group (t(136) = -3.72, p <.001). Similarly, the low resilience group had poorer functional impairment compared to the medium (t(136) = -2.66, p = .009) and high resilience groups (t(136) = -3.08, p = .003), however the medium and high resilience groups did not differ significantly (t(136) = -0.56, p = .578). Thus, when there were overall differences between the three groups, it was primarily due to the lower resilience group. This suggests that degree of resilience may make a difference in terms of reported disease symptoms (e.g., disease symptom-related QOL, functional impairment, NMS); those with comparatively lower resilience also report significantly worse disease symptoms.
Table 8.
*Outcome variables across three resilience groups*

<table>
<thead>
<tr>
<th></th>
<th>Low resilience</th>
<th>Medium resilience</th>
<th>High resilience</th>
<th>F</th>
<th>t</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N = 46</td>
<td>M (SD)</td>
<td>N = 51</td>
<td>M (SD)</td>
<td>N = 42</td>
<td>M (SD)</td>
<td></td>
</tr>
<tr>
<td>Depression^1</td>
<td>18.26 (7.87)</td>
<td>11.04 (5.90)</td>
<td>6.48 (4.19)</td>
<td>41.38</td>
<td>2</td>
<td>119.21</td>
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<td>Low vs. medium</td>
<td></td>
<td>-5.07</td>
<td></td>
<td>82.96</td>
<td>2</td>
<td>136</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Low vs. high</td>
<td></td>
<td>-8.87</td>
<td></td>
<td>69.85</td>
<td>2</td>
<td>136</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Medium vs. high</td>
<td></td>
<td>-4.35</td>
<td></td>
<td>89.19</td>
<td>2</td>
<td>136</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Apathy</td>
<td>16.74 (5.23)</td>
<td>11.55 (4619)</td>
<td>8.07 (5.60)</td>
<td>31.99</td>
<td>2</td>
<td>136</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Low vs. medium</td>
<td></td>
<td>-4.97</td>
<td></td>
<td>136</td>
<td>&lt;.001</td>
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<tr>
<td>Low vs. high</td>
<td></td>
<td>-7.91</td>
<td></td>
<td>136</td>
<td>&lt;.001</td>
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<td>Medium vs. high</td>
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<td>-3.25</td>
<td></td>
<td>136</td>
<td>.001</td>
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<tr>
<td>Life Satisfaction^1</td>
<td>18.61 (6.27)</td>
<td>23.29 (6.58)</td>
<td>28.98 (3.75)</td>
<td>35.21</td>
<td>2</td>
<td>123.22</td>
<td>&lt;.001</td>
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<tr>
<td>Low vs. medium</td>
<td></td>
<td>3.59</td>
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<td>94.70</td>
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<td>Low vs. high</td>
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<td>9.50</td>
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<td>74.59</td>
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<tr>
<td>Medium vs. high</td>
<td></td>
<td>5.22</td>
<td></td>
<td>81.71</td>
<td>2</td>
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<td>&lt;.001</td>
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<tr>
<td>Adjustment-related QOL</td>
<td>31.03 (12.21)</td>
<td>19.61 (11.70)</td>
<td>13.79 (9.47)</td>
<td>27.03</td>
<td>2</td>
<td>136</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Low vs. medium</td>
<td></td>
<td>-4.99</td>
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<td>136</td>
<td>&lt;.001</td>
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<tr>
<td>Low vs. high</td>
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<td>-7.18</td>
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<td>&lt;.001</td>
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<tr>
<td>Medium vs. high</td>
<td></td>
<td>-2.48</td>
<td></td>
<td>136</td>
<td>.014</td>
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<tr>
<td>Nonmotor symptoms</td>
<td>10.37 (3.38)</td>
<td>8.40 (3.86)</td>
<td>9.10 (4.36)</td>
<td>3.19</td>
<td>2</td>
<td>136</td>
<td>.044</td>
</tr>
<tr>
<td>Low vs. medium</td>
<td></td>
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<td></td>
<td>136</td>
<td>.013</td>
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<tr>
<td>Low vs. high</td>
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<td>-1.55</td>
<td></td>
<td>136</td>
<td>.124</td>
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<tr>
<td>Medium vs. high</td>
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<td>0.86</td>
<td></td>
<td>136</td>
<td>.393</td>
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<tr>
<td>Disease symptom-related QOL</td>
<td>35.95 (17.13)</td>
<td>30.23 (16.88)</td>
<td>23.12 (14.02)</td>
<td>6.94</td>
<td>2</td>
<td>136</td>
<td>.001</td>
</tr>
</tbody>
</table>
Homogeneity of variance assumption was not met, therefore Brown-Forsythe $F$ statistical test was used. According to Field (2009), the Brown-Forsythe $F$-ratio is a robust alternative $F$-ratio that weighs the group variance by the inverse of their sample sizes to reduce the impact of large sample sizes with large variance.

Note. Significance values adjusted with a Bonferroni correction, such that the critical value is set to $p < .017$

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<td>$t$</td>
<td>$df$</td>
<td>$p$</td>
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<tr>
<td>Low vs. medium</td>
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<td>.084</td>
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<td>Low vs. high</td>
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<tr>
<td>Medium vs. high</td>
<td>-2.11</td>
<td>136</td>
<td>.037</td>
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<tr>
<td><strong>Functional impairment</strong></td>
<td>.63 (.51)</td>
<td>.38 (.42)</td>
<td>.33 (.45)</td>
<td>5.57</td>
<td>2, 136</td>
</tr>
<tr>
<td>Low vs. medium</td>
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<td><strong>.009</strong></td>
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<td>Low vs. high</td>
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<td><strong>.003</strong></td>
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<tr>
<td>Medium vs. high</td>
<td>-0.56</td>
<td>136</td>
<td>.578</td>
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$^1$Homogeneity of variance assumption was not met, therefore Brown-Forsythe $F$ statistical test was used. According to Field (2009), the Brown- Forsythe $F$-ratio is a robust alternative $F$-ratio that weighs the group variance by the inverse of their sample sizes to reduce the impact of large sample sizes with large variance.

*Note.* Significance values adjusted with a Bonferroni correction, such that the critical value is set to $p < .017$
Discussion

The present study explored the relationships between PD symptoms and mental health/QOL outcomes in a broad age range of PD patients. The project further sought to examine the construct of resilience in a generally older population, integrating the developmental aging and coping literatures with the resilience research rooted in child and adolescent studies. As is well established, advancements in medicine and technology have resulted in a worldwide aging population, along with an increasing prevalence of chronic disease as a common health burden among middle-aged and older adults. It is therefore imperative we learn more about the relationships between demographic, disease, and individual characteristics that can influence or predict quality of life in order to develop targeted and meaningful interventions. One way to conceptualize this focus within the present study is with a goal to reduce excess disability, or disability components that are created by environmental, social, or psychological barriers (Rybarczyk et al., 1992). A chronic, neurodegenerative disease such as PD maintains a degree of certainty regarding eventual functional limitations, at least until neurological and pathophysiological research advances further. Therefore, the results of this study are important for identifying psychological strengths that may buffer against disease symptoms or protect mental health/QOL within a population in which functioning is often compromised.

Main Predictors of Mental Health and QOL

**Demographic predictors.** Age was an initial demographic predictor of depression (older age associated with less depression), however the variable became nonsignificant after resilience was added into the model. This finding is consistent with other research that finds older patients with chronic disease are less depressed than younger chronic disease patients (Cassileth et al., 1984). In the Cassileth et al. study, participants had an average of 4.4 years since diagnosis,
which is less than the approximate 6.5 years since PD diagnosis in the present study. They did find, however, that those whose illnesses had been diagnosed for shorter periods had greater depression and anxiety and poorer overall mental health than those had been diagnosed for longer. In the present study, time since diagnosis may have been a weaker predictor in the final model because most participants had been diagnosed for several years.

Because age is often a proxy for other more potent variables (e.g., years of experience managing other illnesses), it makes sense that age became nonsignificant when resilience was added into the model and suggests their shared variance is better accounted for by the resilience variable. On the other hand, age was a significant predictor of adjustment-related QOL and remained significant even in the most comprehensive statistical model with resilience and related variables included. In this study, self-reported QOL in terms of disease adjustment (emotional well-being, stigma, social support, cognitions, and communication) increased with patient age. These results are consistent with other research that also finds a positive relationship between age and QOL in chronic disease and adjustment (Rustøen et al., 2005; Shamaskin et al., 2012; Wenzel et al., 1999).

The explanation for these findings is not simply that older age leads to better QOL. The literature on aging and coping suggests that because there is a decline in perceived stress and increase in well-being with age, older adults may have better coping skills or use them more effectively (Aldwin, 1991; Aldwin et al., 1996). In the context of chronic disease, however, it is likely that other variables related to the aging process are playing a central role. For example, older adults may have different expectations about disease and disability that makes the disease course less psychologically upsetting compared to younger adults. They might also have more experience around health issues (Aldwin, 1991), greater engagement in downward social
comparison to more ill older adults (Heckhausen & Krueger, 1993), or view the physical experiences and limitations of a chronic disease as a more normative part of aging (Neugarten, 1979; Williamson & Schulz, 2005). Furthermore, these mechanisms for different coping qualities among older adults may interact with each other. One study exploring age differences in coping with chronic pain found that older adults used a wider range of coping strategies than their younger counterparts (Molton et al., 2008). The older adults tended to consistently use an effective cluster of strategies regardless of pain intensity, while younger adults’ coping efforts increased with greater pain severity. Perhaps more years of experience with general health stressors allowed the older adults to have a wider repertoire of coping strategies, be more proactive with their coping prior to increased pain intensity (i.e., proactive coping; Aspinwall, 2005), and have better intuition regarding which strategies would work effectively for them.

Higher income predicted better adjustment-related QOL but became nonsignificant when resilience was added into the model, suggesting that resilience better accounted for the shared variance between the two variables. Income was a robust predictor of life satisfaction and remained significant even in the most comprehensive statistical model. This is presumably because higher income provides greater access to resources important within chronic disease (e.g., access to health care services, transportation, medication) that could improve life satisfaction. A similar phenomenon might explain why more years of education was associated with greater adjustment-related QOL.

Disease symptom-related QOL. Hypothesis 1 was partially supported in the present study. Regarding depression, disease symptom-related QOL (comprised of QOL questions related to mobility, ADLs, and bodily discomfort) was the only significant predictor. This finding is consistent with other research that demonstrates a strong relationship between
depression and QOL (Schrag, 2006). It also confirms the suggestion that the relationship between depression and disease symptoms is dependent on measurement tool. Holroyd et al. (2005)’s research found that depression was more closely related to disease progression when disease progression measurement included disease impact (e.g., ADLs) instead of exclusively physical symptoms (e.g., Hoehn and Yahr scale, which defines levels of motor functioning). Similarly, in the present study, depression was predicted by subscales of the PDQ-39 that were related to disease symptoms and could reflect some adaptation and coping that presumably shaped participants’ responses. Depression was not predicted by other measures that could reflect symptomology or disease progression, such as disease duration or NMS ratings.

In addition to predicting depression, disease symptom-related QOL also significantly predicted adjustment-related QOL, which further adds to the body of literature regarding the multifactorial components of health-related QOL in PD. For example, in Schrag’s (2006) review of depression and QOL, she included studies that demonstrate several disease-related factors as influencing QOL, including freezing, dystonia, and akinesia (Kuopio et al., 2000). These disease-related factors are conceptually similar to the disease symptom-related subscales from the PDQ-39 that made up composite predictor variable in the present study (i.e., mobility, ADLs, and bodily discomfort). There are certain limitations to drawing conclusions from these findings, given that the subscales composing the disease symptom-related QOL variable and adjustment-related QOL variable are from the same parent scale. However, their correlation value ($r = .68, p < .001$) indicates a strong relationship without multicollinearity, thus the composite variables represent distinct components of QOL. These findings further support the idea that disease duration or symptom frequency/severity (e.g., Hoehn and Yahr scale, Nonmotor Symptoms Questionnaire) may not be the best predictors of mental health/QOL outcomes for PD patients;
instead, disease symptoms as they relate to QOL (e.g., mobility, ADLs, bodily discomfort) seem to be the key variables for future study.

**Nonmotor symptoms.** Contrary to hypothesis, neither depression nor apathy were predicted by degree of nonmotor symptoms (NMS). This study posited that because NMS are qualitatively different than motor symptoms, and often underrecognized by treating neurologists, and less likely to be disclosed during medical appointments (Chaudhuri et al., 2010), they might be a useful predictor of mental health outcomes. This hypothesis, however, was not supported. One possible explanation is that patients interpreted NMS as more similar to motor symptoms than originally anticipated. If viewed as simply another uncontrollable or unpredictable element of PD, NMS may not be perceived as modifiable through coping or adjustment; therefore, the degree of NMS would be unrelated to depression. Another reason why NMS was not predictive of apathy or depression may have been because NMSQuest items that were conceptually similar to mental health/QOL outcomes (i.e., neuropsychiatric symptoms: depression, apathy, anxiety, anhedonia, attention deficit, hallucinations, delusions) were excluded from the NMS total score.

NMS also did not predict life satisfaction or adjustment-related QOL, which is inconsistent with other research finding a relationship between NMS and QOL (Martinez-Martin, Rodriguez-Blazquez, Kurtis, & Chaudhuri, 2011). Again, one reason for this finding may be because mental health-related items were eliminated from the NMS total score, while other studies included the entire NMS scale. Therefore, it is possible that the predictive value of NMS lies in the neuropsychiatric symptoms primarily, as they might be the most emotionally draining or depleting (e.g., “loss of interest in what is happening around you or in doing things”, “feeling anxious, frightened, or panicky”, “difficulty concentrating or staying focused”, “believing things are happening to you that other people say are not”). This hypothesized explanation is supported
by other research that finds neuropsychiatric NMS, such as depression, anxiety, and cognitive
decline, are significant contributors to patients’ QOL (Rahman, Griffin, Quinn, & Jahanshashi,
2008). With these symptoms eliminated from the NMS scale in the present study due to
confounds with other variables, the remaining more physical NMS may not have carried the
same emotionality nor be as distressing or disruptive to QOL (e.g., “dribbling of saliva during
the daytime”, “getting up regularly at night to pass urine”, “talking, or moving about in your
sleep, as if you are ‘acting out a dream’”, “double vision”). This explanation would also be
consistent with the relatively high FIM scores in the present study; with a sample population that
has relatively high functional independence, any NMS reported (with neuropsychiatric
symptoms excluded) may not have been very disruptive to daily functioning.

**Functional impairment.** One unusual result from the study was that functional
impairment was not a significant predictor of depression. While there has been some research
establishing the relationship between functional impairment and emerging disability (Shulman et
al., 2008), there has been limited study of the relationship between functional impairment and
mental health in PD patients. There have been numerous studies demonstrating depression as an
important predictor for functional impairment in rehabilitation inpatients post-stroke (see Lenze
et al., 2001 for a review), while other studies find no associations between depression and
functioning (e.g., Dossa, Glickman, & Berlowitz, 2011). However, no studies to this writer’s
knowledge have examined functional impairment as a predictor variable itself. It is therefore
difficult to interpret this finding within the context of other research, however the role of
functional impairment becomes somewhat clearer as a predictor of other dependent variables.

Notably, functional impairment was a significant predictor for the other three mental
health/QOL outcome variables. As a strong predictor of apathy, life satisfaction, and
adjustment-related QOL, functional impairment appears to be a key variable of interest for future research. This is consistent with another study that found degree of disability, as measured by the Schwab and England scale, significantly predicted PDQ-39 SI scores (Rahman et al., 2008). It is possible that the degree to which patients are able to maintain independence in their ADLs has a stronger relationship with broader perceptions/interpretations of one’s life (i.e., life satisfaction and adjustment-related QOL), however it has less influence on mood and internal self-evaluation. This finding also highlights another conceptual difference between depression and apathy, such that patients with greater ADL functioning may be less vulnerable to the apathy components of PD but still at risk for depressive symptoms. Furthermore, the pathophysiological etiology of depression may make the symptoms less malleable to psychological coping in general as compared to apathy, life satisfaction, and QOL.

Taken together, it seems that disease features within the context of coping or adjustment (e.g., ADLs, functional impairment, mobility, and bodily discomfort) are more predictive of mental health and QOL outcomes than more objective disease features (e.g., disease duration, NMS). These trends are consistent with previous PD research (e.g., Suzukamo, Ohbu, Kondo, Kohmoto, & Fukuhara, 2006) and emphasize the value in focusing on changing people’s perceptions of the influence PD has on their QOL. For example, there may be great benefit for PD patient’s QOL and mental health through further research and development of assistive devices that allow people to transport or feed themselves independently. The recently developed “Smart Spoon” is one example of this type of technology (Allen, 2014). This device tracks vibrations and compensates for hand tremors by stabilizing the utensil and allows people with PD to eat without food falling off of their utensil. This type of assistive device would increase functional independence and potentially reduce stigma of eating in public, which would
presumably have positive impacts on apathy, life satisfaction, and adjustment-related QOL.

The present study suggests that subjective experiences and disease features in the context of adjustment and coping are important predictors of mental health/QOL. In this regard, it may be beneficial for clinics or treating clinicians to identify patient’s most distressing disease features (e.g., through QOL questionnaires) and then provide a targeted intervention. High distress regarding illness uncertainty, for example, might warrant interventions that emphasize emotion-focused coping for dealing with disease-related stress outside of one’s control. Other psychological intervention, such as mindfulness meditation, may be beneficial for addressing multiple symptomatic areas within PD. A meta-analysis of interventions using the Mindfulness Based Stress Reduction program with chronically ill patients found consistent improvements in coping and reduced distress and disability (Grossman, Niemann, Schmidt, & Walach, 2004). Quantitative research on mindfulness in PD has been limited, however results from a qualitative study suggested group mindfulness-based cognitive therapy (MBCT) could benefit people with PD through group support and the experience of mindfulness meditation itself (Fitzpatrick, Simpson, & Smith, 2010).

**Resilience**

Although resilience was a significant predictor for all main outcome variables, Hypothesis 2 was not met. Resilience did not moderate the relationship between predictor and outcome variables from Hypothesis 1. This null finding could suggest that people’s perceptions of their resilience or ability to “bounce back” from adversity is not a potent enough variable to affect the relationship between functional impairment and apathy, for example. The most likely explanation for this nonsignificant finding is due to the relatively limited range of responses on the RSA. While there was a normal distribution of scores, participants’ total scores were
aggregated toward the higher end of the scale. It is somewhat puzzling that participants would report relatively high resilience (RSA composed of: family coherence, structured style, social resources, positive perception of self, positive perception of future, and social competence) while still have slightly higher than normative depression and apathy scores. A likely explanation is that the physiologically-based nature of depression and apathy in PD contributed to this higher prevalence of mental health issues. The sample had, on average, PD for a relatively short amount of time, and they were self-selected as participants, therefore they may not have yet reached the point in their disease progression to experience significant adversity. Their perception of their own coping ability and adaptive personal qualities remained strong while they simultaneously experienced physiologically-based mental health symptoms. It would be useful for future research to study other individual psychological factors that might clarify this relationship, for example whether higher resilience affects self-efficacy or locus of control, both of which are known to influence depression (Benassi, Sweeney, & Dufour, 1988; Maciejewski, Prigerson, & Mazure, 2000).

What is the value or utility of self-perceived resilience, if those with even moderate resilience scores are still at risk for poor mental health? Perhaps our conceptualization of resilience within chronic illness is too narrow, as suggested by Trivedi and colleagues (2011). Trivedi et al. posits that the additive effects of chronic disease stressors might drain individual’s psychological reserve, such that the “resilient response” in an individual changes over time depending on their disease course. Similarly, the timing of resilience measurement in chronic illness becomes more complicated; some patients might experience initial distress following diagnosis but regain resiliency over time through disease adjustment, while others might have an initial resilient response but become distressed after lengthy rehabilitation or recovery. Trivedi
proposes an alternate conceptualization of resilience, with the underlying assumption that individuals exist in a state of equilibrium, and resilience is the process through which individuals maintain or regain equilibrium over time. In Trivedi’s model, resilience is a three-level construct with each level indicating different clinical goals. Individuals demonstrating *primary resilience* experience only a brief loss of emotional well-being in response to adversity. They have the resources to achieve optimal outcomes, and their clinical goals are to maintain this equilibrium.

Within the *secondary resilience* level, individuals undergo moderate loss of well-being and subclinical distress, but they are able to achieve the clinical goal to regain their own equilibrium through personality traits, coping styles, and social resources. Those with *tertiary resilience* experience significant loss of well-being and often develop psychiatric symptoms. Their equilibrium is met after a length of time and often with professional intervention.

The advantage of this model with chronic disease populations is the fluidity of intervention matching with the fluidity of the stress response; identifiable clinical goals can shift depending on individual’s changing levels of resilience throughout the disease. Within the context of the present study, the “snapshot” cross-sectional research design leaves several questions unanswered. It is probable that the self-reported resilience reflected participants’ perceptions of their general coping and ability to “bounce back”, perhaps thinking of previous stressors or adversities at earlier points in the disease. Individuals may have viewed themselves as within the primary resilience level, able to use their own resources thus far to cope with their PD, but some may have instead been transitioning to secondary or tertiary resilience levels that put them at higher risk for adverse outcomes. Future research in resilience with chronic disease using this alternative conceptualization may provide further information about the dynamic nature of the construct. Identification of individuals at these different levels might also have
implications for intervention focus. Primary prevention measures could improve and maintain resilience at the time of illness onset/diagnosis and on an ongoing basis; those detected early with poorer coping might benefit from secondary prevention, and finally tertiary prevention would be indicated through active interventions and outside referrals where necessary (Trivedi et al., 2011).

The fact that the resilience variable was still a significant predictor of all main outcome variables suggests that degree of resilience compared to others, more so than total score compared to scale maximum score, is important. The findings from the planned contrasts of the three resilience subgroups supports this explanation; the low resilience group appeared distinct and differed from the medium and high resilience groups more than the medium and high differed from each other. Thus, even those with comparatively lower resilience ($M$ total score = 107.57, max score = 165; $M$ item score = 3.26, max score = 5) seem to have poorer NMS, disease symptom-related QOL, and functional impairment than those with relatively higher resilience. Perhaps there is a minimum resilience threshold, such that those who fall below this threshold have noticeable differences in their perceptions of disease symptoms.

Research findings suggest several methods for improving resilience, though the lack of consensus regarding a definition and conceptualization of resilience poses a challenge for studying resilience-promoting interventions. Some studies emphasize emotion regulation strategies (Tugade & Fredrickson, 2007); one found that in-the-moment positive emotions mediated change in resilience, supporting the broaden-and-build theory that suggests positive emotions build resources to help people deal with life challenges (Cohn, Fredrickson, Brown, Mikels, & Conway, 2009). Other research focusing on promoting psychological resilience in the U.S. military found a range of individual, family, unit, and community-level factors that promote
resilience (Meredith, Sherbourne, & Gaillot, 2011). Most resilience-promotion programs emphasize the individual-level factors, such as positive thinking (which includes positive reframing, making sense out of a situation, flexibility, and reappraisal), positive coping, behavioral control, positive affect, and realism training.

Another way of comparing these differences is through the minimally important difference (MID) estimate. The PDQ-39 manual (Jenkinson, 2008) suggests that MIDs vary between dimensions depending on the subscale, such that subscales with relatively small effect sizes indicate subjectively important changes. With composite scales created in the present study, it is not possible to use the MID suggestions from the PDQ-39 manual itself to interpret results. However, one systematic review of numerous health-related QOL instruments computed effect sizes and concluded that the threshold of discrimination for change in QOL for chronic diseases appears to be one half SD (Norman, Sloan, & Wyrwich, 2003). Using this estimate, the MID for adjustment-related QOL would be 6.61 (adjustment-related QOL $SD = 13.21$). As seen in Table 8, there is not a MID between the medium and high resilience group adjustment-related QOL scores (absolute difference between the groups = 5.82), while the difference between the low resilience group compared to medium and high resilience is 11.42 and 17.24, respectively. The MID for disease symptom-related QOL is 8.42 (disease symptom-related QOL $SD$ is 16.84); there is not a MID between the medium and high resilience disease symptom-related QOL scores (absolute difference between the groups = 7.11), but there is a significant MID between the low and high resilience groups (absolute difference between the groups = 12.83). This adds further evidence to suggest that degree of resilience is important, with relatively lower resilience associated with clinically significant poorer outcomes.

The resilience variable also had the highest standardized $\beta$ within most models,
suggesting that it has the greatest “importance” as a model predictor. For example, as resilience score increased by one standard deviation (17.45 raw score increase on RSA), depression score decreased by 0.51 standard deviations, or 3.95 points on the BDI-II. Similarly, one standard deviation increase in resilience scores predicted a 2.97 point decrease in apathy, a 3.95 point increase in life satisfaction, and 5.81 point decrease in adjustment-related QOL (lower scores indicate better QOL; see discussion above regarding MID for this scale). Resilience was the strongest statistical predictor in the depression and life satisfaction models. Meaning-making ability became a stronger predictor than resilience when added into the apathy model (Table 5).

**Hypothesized Resilience Components**

Hypothesis 3 was partially supported, with other resilience variables serving as significant predictors above and beyond the resilience measure and other PD symptoms. This is a key finding because it suggests that within the context of an older, chronic disease population, there are other important features that affect adjustment and might reflect unique elements of resilience. As discussed in the literature review, the resilience construct was initially developed with younger populations (Rutter, 1989; Werner, 1996), and there continues to be greater integration of the construct into adult and medical population research (Rybarczyk, Emery, Guequierre, Shamaskin, & Behel, 2012; Zautra, Hall, & Murray, 2010). Furthermore, there are unique older adult coping styles and age-related strengths (i.e., adaptive emotion regulation, positivity) that have had relatively limited incorporation into the resilience literature compared to child, adolescent, and family-related variables. To that end, findings from the present study highlight that meaning-making ability, goal flexibility, and optimism deserve more attention in future research as potentially useful focus areas in disease coping and adjustment.

**Meaning-making ability.** Meaning-making predicted both depression and apathy above
and beyond resilience, with participants who reported greater meaningfulness also reporting lower depression and apathy. While meaning-making and resilience were strongly correlated ($r = .71, p < .001$), its significance in Block 3 of the models suggests that meaning-making accounted for some unique variance that was not captured in a standard resilience scale. Furthermore, meaning-making was a stronger predictor of apathy than resilience when entered simultaneously into a multiple regression. This is a critical finding since being able to find positive meaning from adversity is known to be an important coping mechanism (Folkman, 2008; Park & Folkman, 1997). This finding was also anecdotally observed during the missing data follow-up phone calls; numerous participants commented on their gladness to participate in the study because they found it meaningful to share their experience and help future generations of PD patients. The meaningfulness subscale on the SOC essentially measures people’s belief that their lives are meaningful, and life demands are challenges worthy of investment. While one could argue there are differences between meaning-making ability and meaningfulness (see Park, 2010 for an integrated review of the meaning making construct), these semantic nuances should not preclude interpreting the findings in the present study. Meaning-making strategies can be taught or guided through emotion-focused therapy (Greenberg, 2004). Some examples of strategies that promote meaning-making are comparison processes that reduce discrepancies between situational and global meaning, focusing on positive attributes, and benefit finding/reminding (Park, 2010).

These results fit well with research in coping and chronic illness. Meaning-making and other variants of the construct (i.e., meaningfulness, meaning reconstruction, benefit finding) have been found as important variables in adjustment and coping in numerous chronic disease studies, including multiple sclerosis (Mohr et al., 1999), lupus (Katz, Flasher, Cacciapaglia, &
Nelson, 2001) and cancer (Lee, Robin Cohen, Edgar, Laizner, & Gagnon, 2006; Park, Edmondson, Fenster, & Blank, 2008). Other research within PD specifically has found that emotion-regulation coping is most commonly used when dealing with stressful disease symptoms, and even with physical symptoms that may typically be more amenable to problem-focused coping (Frazier, 2000). Frazier suggests that because of the limited control patients maintain over their mobility and motor symptoms (much depends on medication), promotion of emotion-focused coping is critical with PD populations. Given that meaning-making is an important element of the appraisal-emotion-coping-reappraisal process (Folkman, 2008), continued exploration of this construct within PD is warranted.

Although not within PD, Park and colleagues (2008) studied cancer survivors and attempted to differentiate between the meaning making process and meanings made (products of the process). They used mediation analyses and found that meaning-making efforts were related to positive adjustment through the creation of adaptive meanings made (i.e., growth, life meaning), and it was these meaning-making products, more so than the process itself, that were related to well-being. Translating this research to the current study, it may be beneficial for future studies in PD to include different types of scales to assess meaning-related constructs. The present study only used the meaningfulness subscale of the SOC, which presumably reflected a straightforward measure of life meaningfulness. The significant predictive value of this 4-item subscale suggests that meaning-related constructs (meaningfulness, meaning-making ability, and meanings made) account for some unique variance that is not measured through standard resilience scales and are ripe areas for future research. Additional studies could elucidate the nature of these constructs by using more sophisticated or targeted measures, such as the Benefit Finding Scale (Carver & Antoni, 2004; Tomich & Helgeson, 2004) for measuring posttraumatic
growth and the Perceived Personal Meaning Scale (Wong, 1998) for measuring life meaning. Another possibility is that benefit finding has a differential function over the course of chronic disease (Stanton, Bower, & Low, 2006), emphasizing the importance of longitudinal design in this area of research.

There is valuable room for intervention with PD patients to promote meaning-making and other forms of emotion-focused coping that would likely positively affect mental health. Potential interventions could include identifying patients using active problem-solving for challenges that are not likely to change (e.g., tremors) before they become discouraged and/or disengaged, and instead redirect them towards positive re-appraisal and more emotion-focused reflection. The “Lifeline” exercise is one interesting intervention used within cancer research (Lee et al., 2006) and is designed to assist with meaning-making following a stressful health event. This narrative approach guides participants through a review of their negative health experience and encourages them to incorporate their experience into the context of other life events. There is a specific focus on appraising emotional and cognitive responses to the health issue, exploring past coping and how it influences present experiences, and reflection on life priorities with an acknowledgment of mortality. This approach is similar to the Life Narrative Interview, an intervention which reduces anxiety and increases emotion-focused coping among briefly hospitalized patients (Rybarczyk & Auerbach, 1990; Rybarczyk et al., 1993).

**Goal-flexibility.** Goal-flexibility accounted for unique variance above and beyond resilience in predicting life satisfaction, however not for depression, apathy, or adjustment-related QOL. The amount of unique variance accounted for by goal-flexibility, however, was remarkably less than the resilience variable (1.7% vs. 6.9%, respectively). This finding suggests that goal-flexibility may have a small influence on life satisfaction. The current study
hypothesized that goal-flexibility would be a key variable in this aging, chronic disease population, given that the literature suggests that one’s ability to give up unattainable goals and re-engage in new goals is an adaptive coping strategy when functional declines begin to limit ability (Wrosch et al., 2003). These results are somewhat inconsistent with research that finds goal-flexibility significantly impacts depression and physical symptoms among a large sample of community-dwelling middle-aged and older adults (Kelly, Wood, & Mansell, 2013). One explanation for the small effect of goal-flexibility in this study is that participants may not have faced many unattainable goals, therefore one’s ability to disengage and re-engage in other goals was an unnecessary coping strategy in this population. The participants’ relatively high ADL functioning on the FIM measure could support this explanation, such that this sample of participants was highly functional and likely did not need to change their goals or expectations for being able to achieve those goals. In future research measuring goal-flexibility, it would be useful to measure people’s baseline goal expectations or inquire about their required goal-flexibility in regards to disease-specific domains. The flexible goal adjustment subscale of the TEN/FLEX in this study asked about people’s general disposition to tenaciously pursue goals or flexibly adjust their goals. For the purposes of assessing coping and adjustment in chronic disease populations, it might be beneficial to prompt participants to reflect on their goals within specific domains (e.g., transportation, eating, dressing) and then measure their self-perception of goal adjustment or goal pursuit.

It is also possible that the influence of goal-flexibility depended on participants’ level of tenacious goal pursuit. The original TENT/FLEX is validated to administer the flexible goal adjustment and tenacious goal pursuit subscales separately (Brandstädter, & Renner, 1990), but there is recent evidence of a unique interdependent relationship between the two constructs.
Kelly et al. (2013) found a significant interaction between the constructs in predicting well-being, such that individuals who were high in both flexibility and tenacity experienced lower levels of depression. They suggested that tenacious goal pursuit was most beneficial when there was simultaneous goal-flexibility for unattainable tasks; people could benefit from positive goal pursuit without the negative effects of perseveration on unattainable goals. Although beyond the scope of the present study, it is recommended that future research exploring these constructs in more detail assess levels of both flexibility and tenacity.

Participants’ goal-flexibility was a significant predictor of cognitive-affective depression above and beyond resilience, though not a predictor of the full depression scale nor somatic-vegetative depression symptoms. The effect was again relatively small, with goal-flexibility accounting for only 1.6% of the variance. Particularly for this PD population, in which the somatic-vegetative symptoms endorsed on the BDI-II may overlap with other PD symptoms (i.e., low energy, sleep and appetite changes), it may be even more important to identify small mechanisms that can influence mood and self-esteem. Taken together, it seems that goal-flexibility and resilience generally share variance, such that the predictive effect of goal-flexibility is only significant when entered into a model simultaneously with the resilience variable. On the other hand, there seems to be something unique about goal-flexibility and the cognitive-affective components of depression; one’s ability to be flexible in his/her goals has a beneficial impact on the cognitive-affective symptoms of depression (e.g., feelings of guilt, worthlessness) that is not measured on a resilience scale. Future research in this area is warranted to replicate this finding, with the potential outcome to inform clinical practice and promote goal-flexibility as a protective feature against cognitive-affective depression symptoms.

**Optimism.** Optimism did not account for unique variance above and beyond resilience
for depression, apathy, life satisfaction, nor adjustment-related QOL. There is good evidence that optimism and holding positive beliefs about an illness are associated with better mood and health-related QOL in PD (Hurt et al., 2013). A meta-analytic review found that optimism was a significant predictor of positive physical health, with larger effect sizes for studies using subjective versus objective physical health measures (Rasmussen, Scheier, & Greenhouse, 2009). Other research shows, however, that the relationship between optimism and health outcomes is not completely straightforward. In a project using data from the Normative Aging Study, researchers found that the beneficial effects of optimism were not consistent across all domains; optimism greatly benefited psychological well-being, self-rated health, and freedom from bodily pain, however did not affect physical, social, or role functioning (Achat, Kawachi, Spiro, DeMolles, & Sparrow, 2000). In another study, the beneficial effects of optimism were found to be illness-dependent, such that MS patients profited more from optimism than PD patients in terms of physical autonomy and emotion-oriented coping (de Ridder, Schreurs, & Bensing, 2000).

While the role of optimism in health is complex and seems to be domain and illness dependent, it still unclear why the variable was not a significant predictor for any outcome variables. One study found a small but significant effect of optimism on health-related QOL in PD (GPDS Steering Committee, 2002), with optimism simply assessed as self-reported “current feelings of optimism”. Thus, it is most likely that optimism remains a variable of interest, but it was not a robust predictor within the framework of the present study, which was to assess whether optimism accounted for unique variance in the generally older population above and beyond resilience (entered into the last block within hierarchical regression analyses). Optimism and resilience were significantly correlated ($r = .63, p < .001$), and several components of the
resilience construct as measured by the RSA included optimism and positivity-related constructs (i.e., positive perception of self, positive perception of future). One might interpret this generally nonsignificant effect of optimism as due to the common elements between optimism and resilience as measured by the RSA. The resilience variable was a better overall predictor of the outcome variables of interest, and measuring optimism separately did not appear to account for any unique variance.

A similar project found that greater optimism predicted greater benefit finding in MS patients, and improved depression and benefit finding were completed mediated by positive affect and optimism (Hart, Vella, & Mohr, 2008). This research supported the broaden-and-build model (Fredrickson, 1998) and has implications for future study of optimism and positive affect in chronic illness population. Within the context of the current research project, it is possible that the optimal method of measuring optimism and meaning-making is not as two discrete variables each expected to account for unique components of resilience. Instead, as discovered the Hart (2008) study, perhaps the significant effect of meaning-making on reducing depression and apathy was partially mediated by optimism. This partial mediation relationship was tested and supported in the present study; however, optimism partially mediated the relationship between meaning-making and depression but not meaning-making and apathy. Consistent with the research that highlights the conceptual differences between depression and apathy in PD populations (Leentjens et al., 2008), it seems that optimism partially accounts for the protective effect of meaning-making ability on depression, but it has no influence on how meaning-making ability affects apathy. Fredrickson’s (1998) broaden-and-build model also supports these results, such that optimism as part of the reciprocal relationship between finding positive meaning and positive emotionality plays a key role in the “upward spiral” of emotional well-being. Apathy, on
the other hand, is a more focused symptom cluster reflecting a “disorder of motivation” (Leentjens et al., 2008) in which optimism may not have a prominent role. There are, of course limitations to determining the causal nature of these effects due to the cross-sectional study design. If this project were to be replicated with a longitudinal design, this would be a pertinent hypothesis to test how the broaden-and-build model helps clarify our understanding of positive emotions in the resilience process.

Moderating Effect of Age

Interestingly, age was a significant moderator in the opposite direction than predicted in Hypothesis 4. Patient age affected the meaning-making-depression relationship and the optimism-adjustment-related QOL relationship, such that the protective effects of meaning-making and optimism was greatest for younger patients. The initial hypothesis of the current project suggested that because emotional meaning and positivity are particularly adaptive and salient within older populations (Carstensen et al., 2003), the protective nature of these variables would be heightened with increasing age. One explanation for the reverse finding is that the degree of meaning-making or optimism in the older participants may be more stable or fixed and therefore have less powerful effects on outcomes. For the younger participants who have comparatively less experience or practice coping, it is possible that those who have developed adaptive meaning-making coping or optimistic outlooks experience significant benefit regarding mental health/QOL. This idea is consistent with other hypotheses that older adults’ prior experiences and illness familiarity affect how they cope (Esyenck, 1983), while younger adults facing health stressors are in novel positions to shape or redefine their future goals and expectations (Bombardier et al., 2010). Bombardier et al.’s review of aging and psychological functioning within disability found multiple studies that demonstrated greater benefit finding and
posttraumatic growth among younger samples. They attributed this trend to the developmental positioning of younger adults when faced with disability or major health stressors; they may be more likely to shift their world-view or schemas to fit redefined goals. Older adults that view health stressors as a more “on-time” event (Neugarten, 1979) may be less stressed by the event and therefore less prone to readjust existing schemas or find new meaning from the event. On the other hand, a diagnosis of PD may involve some adjustment features different than other chronic illnesses. Because most people with PD do not have a family history of the disease, the diagnosis is often unexpected. Furthermore, the timing of illness onset can co-occur with retirement, another stressful life event. It would be valuable to study how this moderating effect of age functions in other chronic illnesses with different onset and course.

There was also a significant moderated (by age) mediation between meaning-making ability, resilience, and depression. For younger patients, the effect of meaning-making on depression was directly related, while this relationship was fully mediated by the resilience variable for the older patients. This suggests that meaning-making ability contributes to improved resilience in older adults, which then in turn reduces depression. Implications for this finding suggest that meaning-making ability is a key variable in reducing depression, however the mechanism of change differs depending on patient age. For younger patients, CBT-based interventions that help people positively reframe or enhance the meaning of their disease may be particularly central for targeting depression. For the older patients, their ability to make meaning from their disease seems to contribute to their more global sense of resilience, which then improves depression. Of note, there are likely other factors that differentiate the older and younger patient groups beyond the median age split, such as employment status (e.g., working vs. retired). This would be an important area to investigate in future studies. Perhaps when
individuals are challenged to make meaning of their disease while also maintaining a work role and responsibility as a family provider, there is a stronger direct effect on mental health than when they are retired and have fewer roles that are presumably affected by PD.

The relationship between age and optimism is quite complex and warrants further discussion. Optimism is a known strong predictor of well-being among older adults, although some research finds this relationship is mediated by social support and perceptions of control (Ferguson & Goodwin, 2010). Optimism is often considered a stable personality trait that does not change with age, however some research suggests that optimism and pessimism are separate constructs (Mroczek, Spiro, Aldwin, Ozer, & Bossé, 1993) and become more independent with increasing age (Robinson-Whelan, Kim, MacCallum, & Kiecolt-Glaser, 1997). It is also important to differentiate between optimism and positive affect; both positive and negative affect decrease with age, though positive affect tends to remain more stable over time (Charles et al., 2001). The positivity effect is an example within cognitive psychology of increasing age associated with greater positivity in studies of preference, attention, and memory (Mather & Carstensen, 2005), with positive bias often conceptualized as a pronounced decrease in negativity (Charles, Mather, & Carstensen, 2003; Shamaskin et al., 2010). Other studies suggest that affect within the context of socioemotional aging (Carstensen et al., 2003), accommodative vs. assimilative processes (Brandtstädter & Renner, 1990), and general meaning-making processes are culture-dependent (Fung, 2013). Thus, there are numerous avenues to pursue in explaining the moderating effect of age on the relationship between optimism and QOL in the current study.

One explanation for this differential effect of optimism with age lies in the nuanced differences between optimism and explanatory style (Isaacowitz, 2005). Isaacowitz argues that
optimism as a dispositional trait is a more global, self-relevant construct that individuals carry with them through different situations, while explanatory style may have different levels at various points throughout adult development depending on domain. In line with socioemotional selectivity theory, he found that positive explanatory style in the interpersonal domain was greater among older compared to younger adults. On the other hand, Isaacowitz’s study found that the relationship between optimism and well-being did not vary by age. It is possible that the disease-specific population in the present study is one reason why the moderation results are inconsistent with his findings. The population in Isaacowitz’s study (2005) included a wide age range (youngest participants 18 years old) and community-dwelling older adults. Therefore, there may be something unique about how age, optimism, and well-being functions in PD patients that is unseen in the normative healthy population. Perhaps the diagnosis of a progressive, neurodegenerative disease has differential effect on comparatively younger patients, such that their ability to engage in meaning-making or maintain an optimistic perspective is particularly adaptive.

It is clear that future research in this domain would benefit from studying explanatory style (the stylistic way in which people explain events that happen in their lives; Seligman, 1990) within the context of chronic disease as it overlaps with dispositional optimism/pessimism and conceptual similarities to meaningfulness and meaning-making. Smith and Spiro (2002) also highlight the importance of exploring the moderating effect of age and life stage on the relationship between personality and health outcomes. They suggest that life stage or personality characteristics may affect health change patterns over time, again highlighting the value of longitudinal research in understanding these how these lifespan theories can manifest in empirical data.
There may also be measurement issues that contributed to this finding. This study used a relatively straightforward measure of dispositional optimism (LOT-R) and a study-specific measure of QOL (a composite of adjustment-related QOL subscales from the PDQ-39); therefore, one must exercise caution in comparing these findings with other studies that measure other variants or extensions of optimism (e.g., positivity, positive affect, optimistic explanatory style) or QOL (e.g., psychological well-being, subjective well-being, general health-related QOL). Future research might benefit from measuring optimism, both positive and negative affect (e.g., Positive and Negative Affect Scale; Watson, Clark, & Tellegen, 1988), and other potential mediating effects such as social support and perceived sense of control in a longitudinal design.

**Illness Uncertainty and Spirituality**

Illness uncertainty was a small but significant predictor for all outcome measures except apathy. This finding is consistent with other PD research that found illness perceptions (illness identity, chronicity, perceived consequences, and personal control) affected depression and psychological adjustment (Evans & Norman, 2009) and had a negative psychological impact for both patients and caregivers (Sanders-Dewey, Mullins, & Chaney, 2001). Illness uncertainty has also been highlighted as particularly salient within qualitative interviews of PD patients (Stanley-Hermanns & Engebretson, 2010). In their interviews, participants often reflected on general day-to-day activities but were unable to describe a typical day due to the unpredictable nature of PD. The overarching study theme was captured by the authors in a metaphor “Sailing the Sea in the Eye of the Storm”, with the subthemes as “Daily Negotiations in the Midst of Uncertainty” (the storm), and “Reconstruction of the Self” (the traveler’s voyage). These qualitative findings share some similarities to the results in the present study. The theme of “Daily Negotiations in the Midst of Uncertainty” essentially reflected that PD determines what each person does on any
given day depending on their physical, psychological, and emotional state. This central theme of uncertainty parallels the significant predictive value of the single “illness uncertainty” question in the present study. The “Reconstruction of the Self” theme represented participant’s tendency to reflect on their voyage of PD and its impact on how they redefined their own sense of self, which ties nicely with the role of meaning-making as a significant predictor in many models in the current study.

One potential reason why illness uncertainty was not a significant predictor of apathy could be that apathy symptoms may be generally less influenced by disease characteristics. For example, as seen in the Stanley-Hermanns and Engebretson study (2010), interviewees explained that the PD experience of constant change required constant self-evaluation, such that they determined what activities they would engage in based on their self-assessment of physical, psychological, and emotional well-being. Thus, if an individual was highly apathetic, they would presumably not engage in much self-evaluation, and their perception of illness uncertainty would not affect their apathy level. Given the increased interest in apathy as a clinical characteristic of PD (Leentjens et al., 2008) and its relationship with QOL (Oguru et al., 2010), it is noteworthy that illness uncertainty, which is a consistent predictor of other outcome variables, does not seem to affect apathy. Additionally, research shows that apathy is connected to the physiological changes in PD, specifically frontal lobe dysfunction and frontal-subcortical circuits (Pluck & Brown, 2002), and is likely not a reaction to illness uncertainty. This data is also further evidence that apathy and depression are distinct constructs within PD and may not respond equally to intervention (Kirsch-Darrow et al., 2006).

Spirituality was not a significant predictor in the current study, however it was a predominant area in many participant’s descriptions in qualitative research (Stanley-Hermanns &
There has been a great deal of research on spirituality and its beneficial role in health (see Koenig, 2013 for a review; Pargament, Koenig, Tarakeshwar, & Hahn, 2004), with religion and spirituality beliefs and practices often used to cope with challenges of physical illness. Spirituality and religion have also been interwoven into resilience research (Faigin & Parament, 2011); religion can help provide a framework through which people can engage in meaning-making and help them control, predict, and understand otherwise uncontrollable negative life events (Park, Folkman, & Bostrom, 2001). Langer (2004) highlighted the role of religious coping with older adults in particular, providing a model for a strength-based approach to counseling that helps older adults integrate their spirituality into their individual resiliency.

Given the prevalence of spirituality and religiosity in resilience and coping, it is surprising that spirituality was not a significant predictor in the present study. The most likely explanation for this nonsignificance is that the variable was created as a composite of three spirituality question items drawn from another resilience scale (the CD-RISC). The resilience scale used in the study (RSA) was chosen for its psychometric properties, interpretability, and because the scale developers included older adults in their development sample. Spirituality items were included in the present study as an adjunct because the RSA did not include any items or subscales regarding spirituality. In future studies, it is recommended to include a validated measure of spirituality or religious coping, such as the RCOPE (Koenig, Pargament, & Nielsen, 1998), brief RCOPE (Pargament, Koenig, Tarakeshwar, & Hahn, 2001), or Spiritual Well-Being Scale (Belcher, Dettmore, & Holzemer, 1989). These validated measures would provide a more psychometrically sound assessment of participants’ levels of spirituality/religiosity and allow for comparison to other research using the same scales.

Limitations
Several limitations in this study must be noted. Participants were recruited through convenience sampling, which could have led to a biased group with characteristics not reflective of the PD population in general. The study was advertised to those who sought treatment through the Parkinson’s and Movement Disorders Center (PMDC), attended various PD support groups throughout Virginia, and those who saw advertisements online through the PMDC website. Therefore, participants were likely a self-selected group who were engaged with their care and motivated to learn about PD. While average scores on several study measures seemed to match well with other PD samples, it is possible that this sample was biased to include a generally healthier group of PD patients that were well enough to seek out and participate in studies. It would be important for future studies to include several sampling methods (e.g., random and convenience) from multiple sources (community-based sources, general hospital populations, PD specialty clinics) to get the widest variety of PD patients. This would allow for greater generalization of findings to other PD samples. Furthermore, although the statistical models were designed based on theory, the models found in this study might capitalize on the particular properties of this sample, and results should be confirmed with another PD group.

Similarly, the findings from the present study may not extend to PD patients with significant cognitive impairment or dementia. Degree of cognitive impairment was not measured in the present study; however, of the 66 participants who had completed a baseline neuropsychological evaluation at the VCU PMDC and given consent for their records to be used for research purposes, 2 had a diagnosis of dementia and 46 (or 33% of entire sample) met criteria for MCI. Rates of MCI in PD clinic samples are typically around 25-30% (Aarsland et al., 2010). Therefore, the present sample is comprised of responses from individuals with comparable MCI prevalence rates to other clinic samples. Evaluations were not completed on all
sample participants, however, therefore further analyses compared the known vs. unknown samples regarding cognitive impairment. The “known” sample was defined as the 66 participants who received prior neurocognitive evaluations at the PMDC, while the “unknown” sample was defined as the remaining 73 participants.

The two groups were compared on all demographic, control, and outcome variables. Independent samples t-tests indicated that the groups differed significantly in terms of age, with the average age of “known” sample of participants who received neurocognitive testing approximately 5 years older than the “unknown” sample that did not receive testing; $t(137) = 2.89, p = .005$. This group difference is not unusual, as one might expect that those patients who sought out and received neurocognitive testing would be older. The two groups did not differ on all other demographic, control, and outcome variables.

It is likely that those with significant cognitive impairment self-selected out of the study due to the cognitive resources necessary to complete the survey. Because dementia in PD is relatively common (24%-31%; Aarsland et al., 2005), it would be worthwhile to test how the relationships between these variables may differ in individuals with PD with greater cognitive impairment. Further research in this area would greatly benefit from a broader sample of PD patients with a wider range of functioning, as participants in the present study reported very high functional independence.

As previously discussed, one major limitation to this study was the cross-sectional design. With resilience generally thought of as recovery, sustainability, and growth through adversity (Zautra, Arewakisporn, & Davis, 2010; Zautra, Hall, & Murray, 2010), there remains debate whether resilience is a dispositional trait or a process that develops over time. In the present study, it was difficult to determine the causal effect of participants’ self-reported
resilience. While greater resilience was associated with generally better outcomes in terms of mental health/QOL, one cannot conclude that having higher self-perceived resilience actually protected against adverse outcomes. An ideal longitudinal study might measure PD patient’s resilience, mental health/QOL, and disease symptoms at multiple time points throughout the disease. With this type of design, one could analyze whether levels of self-reported resilience at one time point could predict outcomes at a later time point. One could also examine whether resilience levels remained constant within individuals or developed over time throughout the disease, which would help clarify the trait vs. process argument in resilience literature. Further mediation tests could be conducted with a longitudinal design, as well. This would be useful for confirming the mediating effect of optimism found in the present study, and it could also test whether the effect of benefit-finding does change over the course of chronic disease, as suggested by Stanton and colleagues (2006).

Lastly, there are certain limitations with measuring resilience using a self-report scale. The RSA was chosen in the present study due to the multiple sub-factors that matched well onto several resilience definitions and because the scale developers included older adults in their validation study. However, the resilience construct is multifactorial and there continues to be debate over the definition, particularly within an older population or chronic disease context (Smith & Hayslip, 2012; Trivedi et al., 2011). It is unclear when resilience should be measured (e.g., before, during, or after adversity), whether the assessment must occur in the context of adversity, if stressors carry the same associated risk over the lifespan, or if adversity is even required for resilience development.

Coon (2012) argues that multi-level and multi-method approaches may hold the most potential for studying late life resilience, for example by incorporating cultural variables,
accessibility and acceptability of services, and organizational factors to understand resilience in caregiving. Others suggest that the construct of resilience, and subsequent measurement, need to be adjusted within an older population (Smith & Hayslip, 2012), such that late life resilience reflects maintenance of developmental capacities in the face of cumulating challenges (Ong et al., 2009) instead of recovery from risk and adversity. Clarifying the resilience construct in an older population was a primary goal of the present study, which is why meaning-making ability, goal-flexibility, and optimism were measured in addition to the standard resilience scale. The limitations of how resilience was assessed in this study in some regard reflect the state of the resilience literature and challenges integrating the construct into mental and physical health domains. It is hoped that these findings will add to our understanding of late life resilience and clarify next steps for future research.

**Summary and Conclusions**

This study provided important contributions to several areas within psychological and health literatures. First, resilience appears to play a critical role in the relationship between disease variables and mental health/QOL outcomes, particularly for those with moderate self-reported resilience. While the majority of people rated themselves as relatively resilient in terms of social resources and competence, structured style, family coherence, and perceptions of self and future (RSA subscales), those that believe themselves to be slightly weaker in these domains compared to others had worse disease-related symptoms. It is therefore the degree of resilience that appears to be a critical factor; the protective value of resilience was strongest for those who viewed themselves as highly resilient.

Furthermore, other coping factors represented some resilience elements that were not captured on a standard resilience scale, primarily meaning-making ability and goal-flexibility.
These other variables accounted for unique variance not encompassed by the resilience scale, which warrants further exploration of these variables in the resilience and chronic disease literature. Of note, the effectiveness of these factors was dependent on patient age. Younger patients with PD compared to older patients appeared to gain more psychological benefit from being able to draw meaning from their life circumstance and maintain an optimistic perspective. This finding has key clinical implications, for example promoting emotion-focused coping interventions with early-onset PD patients. Results from this study also argue for further integration of a developmental perspective into our conceptualization and measurement of resilience. Research into the effect of age within this literature may alter how we measure (i.e., what scale components), track (i.e., measuring growth through longitudinal designs), and promote (i.e., age-specific interventions) resilience. It will also be important for future studies to discern the underlying mechanism behind these age-related effects, for example examining other experience-related variables (e.g., age at onset, years since diagnosis, comorbid conditions) that may be truer reflections of the actual relationships between these variables.

This project adds to the sparse literature on resilience within PD. As an empirical examination of the construct with a moderate sample size of PD patients and several psychometrically sound measures, this study can serve as a platform for other studies in this area. First, this sample appears comparable to other studies in several domains, suggesting that this group is a normative sample. Mental health prevalence rates were only slightly higher than other PD populations (Kirsch-Darrow et al., 2011) and scores on resilience measures were very similar to other PD samples (Caap-Ahlgren & Dehlin, 2003) and large normative populations (Friborg et al., 2009). This study is also the first to the author’s knowledge to measure resilience in PD with the widely-used Resilience Scale for Adults. Second, there were several areas in this project in
which disease-related variables affected depression and apathy differently, which further adds to the literature emphasizing the unique nature of apathy within PD as more than a symptom of depression. Finally, the relationships between disease symptoms and mental health/QOL in PD appeared more difficult to change than originally hypothesized; despite resilience as strongly related to mental health and QOL, overall it did not seem to affect the relationship between disease symptoms and mental health/QOL outcomes. Perhaps the progressive, neurodegenerative nature of PD, as well as the underlying pathophysiology of depression symptoms, make these areas less malleable to individual coping variables than in other chronic diseases (e.g., Friborg et al., 2006). It would be beneficial for other studies to further examine how resilience functions within PD, for example whether the uncertainty of disease progression warrants measuring resilience as a three-level construct that correlates to different clinical goals throughout the disease (Trivedi et al., 2011).

Demographic predictions worldwide indicate a growing portion of older adults and more people living with chronic disease. These trends have created a shift in the nature of our health and subsequent healthcare, which underscores the need for research to investigate improving quality of life and psychological well-being in the face of disease and adversity. The current project highlights the central role of resilience in this process, as well as some of the limitations in our conceptualization and measurement of the construct within an older disease population. As an area with great potential for intervention and treatment, the implications of this research trajectory could have far-reaching effects towards enhancing the quality of people’s lives as they live with chronic disease.
List of References


Robinson-Whelen, S., Kim, C., MacCallum, R. C., & Kiecolt-Glaser, J. K. (1997). Distinguishing optimism from pessimism in older adults: Is it more important to be optimistic or not to be pessimistic?. *Journal of personality and social psychology, 73*(6), 1345.


questionnaire (NMS-Quest), Parkinsonism and Related Disorders, 18, 54–58. doi:10.1016/j.parkreldis.2011.08.013


Appendix

List of Measures:

*The Resilience Scale for Adults*

*Sense of Coherence Scale*

*Tenacious Goal Pursuit/Flexible Goal Adjustment scales*

*Nonmotor Symptoms Questionnaire*

*The Functional Independence Measure Self-Report*

*Starkstein Apathy Scale*

*Parkinson’s Disease Questionnaire*

*The Revised Life Orientation Test*

*Beck Depression Inventory-II*

*Satisfaction with Life Scale*
The Resilience Scale for Adults (Friborg et al., 2005)

**Personal strength/Perception of self**
- When something unforeseen happens
- My personal problems
- My abilities
- My judgements and decisions
- In difficult periods I have a tendency to
- Events in my life that I cannot influence

<table>
<thead>
<tr>
<th>Always find a solution</th>
<th>Often feel bewildered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly believe in</td>
<td>Know how to solve</td>
</tr>
<tr>
<td>I often doubt</td>
<td>I am uncertain about</td>
</tr>
<tr>
<td>View everything gloomy</td>
<td>I trust completely</td>
</tr>
<tr>
<td>I manage to come to terms with</td>
<td>Find something good that help me thrive</td>
</tr>
<tr>
<td></td>
<td>Are a constant source of worry/concern</td>
</tr>
</tbody>
</table>

**Personal strength/Perception of future**
- My plans for the future are difficult to accomplish
- My future goals uncertain
- I feel that my future looks very promising
- My goals for the future are clear thought through

<table>
<thead>
<tr>
<th>Clear goal to strive for</th>
<th>One day at a time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rarely plan ahead, just get on with it</td>
<td>I prefer to have a thorough plan</td>
</tr>
<tr>
<td>Organizing my time</td>
<td>Wasting my time</td>
</tr>
<tr>
<td>Are absent in my everyday life</td>
<td>Simplify my everyday life</td>
</tr>
</tbody>
</table>

**Structured style**
- I am at my best when I have a clear goal to strive for
- I rarely plan ahead, just get on with it
- I manage to organize my time
- I am good at keeping a positive outlook on the future
- I have difficulty making decisions
- I have difficulty making decisions
- I have difficulty making decisions
- I can take one day at a time
- I prefer to have a thorough plan
- I simplify my everyday life

**Social competence**
- I enjoy being together with other people
- I am good at making new friends
- Meeting new people is easy
- When I am with others I make easily
difficult for me
- I am good at

<table>
<thead>
<tr>
<th>Important to me</th>
<th>Not important to me</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is really important to me</td>
<td>Is really important to me</td>
</tr>
<tr>
<td>I have difficulty making something</td>
<td>I am good at</td>
</tr>
<tr>
<td>I am good at</td>
<td>I am good at</td>
</tr>
<tr>
<td>I am good at</td>
<td>I am good at</td>
</tr>
<tr>
<td>I am good at</td>
<td>I am good at</td>
</tr>
</tbody>
</table>

**Family cohesion**
- My family's understanding of what is important to me is quite different than mine
- My family's understanding of what is important to me is very different than mine
- My family is characterized by a lot that is going on
- In difficult periods my family keeps a positive outlook on the future
- Facing other people, our family acts unsupportive of one another
- We do not have the same values
- In my family we like to do things on our own

<table>
<thead>
<tr>
<th>Similar to mine</th>
<th>Very similar to mine</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very different from</td>
<td>Very different from</td>
</tr>
<tr>
<td>Healthy coherence</td>
<td>Healthy coherence</td>
</tr>
<tr>
<td>Views the future as gloomy</td>
<td>Views the future as gloomy</td>
</tr>
<tr>
<td>Loyal towards one another</td>
<td>Loyal towards one another</td>
</tr>
<tr>
<td>Do things together</td>
<td>Do things together</td>
</tr>
</tbody>
</table>

**Social resources**
- I can discuss personal issues with friends/family members
- Those who are good at encouraging me are friends/family members
- The bonds among my friends are strong
- When a family member experiences a crisis/emergency I get informed right away
- When needed, I have no one who can help me
- My close friends/family members appreciate my qualities

<table>
<thead>
<tr>
<th>Close friends/family members</th>
<th>Friends/family members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strong</td>
<td>Strong</td>
</tr>
<tr>
<td>It takes quite a while before I am told</td>
<td>It takes quite a while before I am told</td>
</tr>
<tr>
<td>No one</td>
<td>No one</td>
</tr>
<tr>
<td>Always someone who can help me</td>
<td>Always someone who can help me</td>
</tr>
<tr>
<td>Dislike my qualities</td>
<td>Dislike my qualities</td>
</tr>
</tbody>
</table>

159


Sense of Coherence Scale- 13 (Antonovsky, 1993)

Here is a series of questions relating to various aspects of our lives. Each question has seven possible answers. Please mark the number which expresses your answer, with numbers 1 and 7 being the extreme answers. If the words under 1 are right for you, circle 1; if the words under 7 are right for you, circle 7. If you feel differently, circle the number which best expresses your feeling. Please give only one answer to each question.

1. (ME) Do you have the feeling that you don’t really care about what goes on around you?*

   
   
   

2. (C) Has it happened in the past that you were surprised by the behavior of people whom you thought you knew well?*

   
   
   

3. (MA) Has it happened that people whom you counted on disappointed you?*

   
   
   

4. (ME) Until now your life has had:

   
   
   

5. (MA) Do you have the feeling that you’re being treated unfairly?

   
   
   

160
6. (C) Do you have the feeling that you are in an unfamiliar situation and don’t know what to do?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>very often</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>very seldom or never</td>
</tr>
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</table>

7. (ME) Doing the things you do every day is:*

<table>
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<tr>
<th></th>
<th>1</th>
<th>2</th>
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<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>a source of deep pleasure and satisfaction</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>a source of pain and boredom</td>
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</table>

8. (C) Do you have very mixed-up feelings and ideas?

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<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
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<tbody>
<tr>
<td></td>
<td>very often</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>very seldom or never</td>
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</table>

9. (C) Does it happen that you have feelings inside you would rather not feel?

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<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>very often</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>very seldom or never</td>
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</table>

10. (MA) Many people – even those with a strong character – sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past?*

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<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>never</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>very often</td>
</tr>
</tbody>
</table>

11. (C) When something happened, have you generally found that:

<table>
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<th></th>
<th>1</th>
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<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>you overestimated or underestimated its importance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>you saw things in the right proportion</td>
</tr>
</tbody>
</table>
12. **(ME)** How often do you have the feeling that there’s little meaning in the things you do in your daily life?

   1. very often 2 3 4 5 6 7 very seldom or never

13. **(MA)** How often do you have feelings that you are not sure you can keep under control?

   1. very often 2 3 4 5 6 7 very seldom or never

* Items are negatively worded and reverse scored; total sum score ranges from 13 to 91.

The notation to the left of each item’s corresponding subscale: C = comprehensibility, MA = manageability, ME = meaningfulness
Tenacious Goal Pursuit/Flexible Goal Adjustment scales (Brandtstadter & Renner, 1990)

The following statements deal with reactions you may have to various situations in which it is difficult to pursue personal goals or plans.

Please indicate your degree of agreement with each statement by providing a rating on a scale ranging from −2 (‘strongly disagree’) to +2 (‘strongly agree’):
<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. When I get stuck on something, it's hard for me to find a new approach.</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>+1</td>
</tr>
<tr>
<td>2. The harder a goal is to achieve, the more appeal it has to me.</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>+1</td>
</tr>
<tr>
<td>3. I can be very obstinate in pursuing my goals.</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>+1</td>
</tr>
<tr>
<td>4. I find it easy to see something positive even in a serious mishap.</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>+1</td>
</tr>
<tr>
<td>5. When faced with obstacles, I usually double my efforts.</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>+1</td>
</tr>
<tr>
<td>6. To avoid disappointments, I don't set my goals too high.</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>+1</td>
</tr>
<tr>
<td>7. Even when things seem hopeless, I keep on fighting to reach my goals.</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>+1</td>
</tr>
<tr>
<td>8. When everything seems to be going wrong, I can usually find a bright side in a situation.</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>+1</td>
</tr>
<tr>
<td>9. I tend to lose interest in matters where I cannot keep up with others.</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>+1</td>
</tr>
<tr>
<td>10. I find it easy to give up on a goal if it seems difficult to achieve.</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>+1</td>
</tr>
<tr>
<td>11. When I run up against insurmountable obstacles, I prefer to look for a new goal.</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>+1</td>
</tr>
<tr>
<td>12. Life is much more pleasurable when I do not expect too much from it.</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>+1</td>
</tr>
<tr>
<td>13. I create many problems for myself because of my high demands.</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>+1</td>
</tr>
<tr>
<td>14. When I have tried hard but cannot solve a problem, I find it easy just to leave it unsolved</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>+1</td>
</tr>
<tr>
<td>15. In general, I am not upset very long about a missed opportunity.</td>
<td>-2</td>
<td>-1</td>
<td>0</td>
<td>+1</td>
</tr>
</tbody>
</table>

... to be continued
### Scoring the TGP/FGA Scales

<table>
<thead>
<tr>
<th></th>
<th>Tenacious Goal Pursuit (TGP)</th>
<th>Flexible Goal Adjustment (FGA)</th>
</tr>
</thead>
<tbody>
<tr>
<td>16.</td>
<td>I adapt quite easily to changes in plans or circumstances.</td>
<td>-2</td>
</tr>
<tr>
<td>17.</td>
<td>I usually find something positive even when giving up something I cherish.</td>
<td>-2</td>
</tr>
<tr>
<td>18.</td>
<td>I avoid grappling with problems for which I have no solution.</td>
<td>-2</td>
</tr>
<tr>
<td>19.</td>
<td>I usually have no difficulties in recognizing where my limits are.</td>
<td>-2</td>
</tr>
<tr>
<td>20.</td>
<td>If I find I can not reach a goal, I’d prefer to change my goal than to keep struggling.</td>
<td>-2</td>
</tr>
<tr>
<td>21.</td>
<td>After a serious drawback, I soon turn to new tasks.</td>
<td>-2</td>
</tr>
<tr>
<td>22.</td>
<td>Faced with a serious problem, I sometimes simply pay no attention to it.</td>
<td>-2</td>
</tr>
<tr>
<td>23.</td>
<td>If I don’t get something I want, I take it with patience.</td>
<td>-2</td>
</tr>
<tr>
<td>24.</td>
<td>Faced with a disappointment, I usually remind myself that other things in life are just as important.</td>
<td>-2</td>
</tr>
<tr>
<td>25.</td>
<td>I find that even life’s troubles have their bright side.</td>
<td>-2</td>
</tr>
<tr>
<td>26.</td>
<td>It is very difficult for me to accept a setback or defeat.</td>
<td>-2</td>
</tr>
<tr>
<td>27.</td>
<td>Even when a situation seems hopeless, I still try to master it.</td>
<td>-2</td>
</tr>
<tr>
<td>28.</td>
<td>I stick to my goals and projects even in face of great difficulties.</td>
<td>-2</td>
</tr>
<tr>
<td>29.</td>
<td>When I get into serious trouble, I immediately try to figure out how to make the best out of the situation.</td>
<td>-2</td>
</tr>
<tr>
<td>30.</td>
<td>I’m never really satisfied unless things measure up to my wishes exactly.</td>
<td>-2</td>
</tr>
</tbody>
</table>

**Scoring the TGP/FGA Scales**

Flexible Goal Adjustment (FGA): 1*, 4, 8, 13*, 15, 16, 17, 19, 21, 23, 24, 25, 26*, 29, 30*

* Reverse items.
Non-motor symptoms questionnaire

Name: ____________________________ Date: ____________ Age: ____________
Centre ID: ________________________ Male ☐ Female ☐

Non-movement problems in Parkinson’s
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?

<table>
<thead>
<tr>
<th></th>
<th>Dribbling of saliva during the daytime.</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Loss or change in your ability to taste or smell</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>3</td>
<td>Difficulty swallowing food or drink or problems with choking</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>4</td>
<td>Vomiting or feelings of sickness (nausea)</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>5</td>
<td>Constipation (less than three bowel movements a week) or having to strain to pass a stool</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>6</td>
<td>Bowel (faecal) incontinence</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>7</td>
<td>Feeling that your bowel emptying is incomplete after having been to the toilet</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>8</td>
<td>A sense of urgency to pass urine makes you rush to the toilet</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>9</td>
<td>Getting up regularly at night to pass urine</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>10</td>
<td>Unexplained pains (not due to known conditions such as arthritis)</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>11</td>
<td>Unexplained change in weight (not due to change in diet)</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>12</td>
<td>Problems remembering things that have happened recently or forgetting to do things</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>13</td>
<td>Loss of interest in what is happening around you or in doing things</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>14</td>
<td>Seeing or hearing things that you know or are told are not there</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>15</td>
<td>Difficulty concentrating or staying focussed</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>16</td>
<td>Feeling sad, ‘low’ or ‘blue’</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>17</td>
<td>Feeling anxious, frightened or panicky</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>18</td>
<td>Feeling less interested in sex or more interested in sex</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>19</td>
<td>Finding it difficult to have sex when you try</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>20</td>
<td>Feeling light-headed, dizzy or weak standing from sitting or lying</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>21</td>
<td>Falling</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>22</td>
<td>Finding it difficult to stay awake during activities such as working, driving or eating</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>23</td>
<td>Difficulty getting to sleep at night or staying asleep at night</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>24</td>
<td>Intense, vivid or frightening dreams</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>25</td>
<td>Talking or moving about in your sleep, as if you are ‘acting out’ a dream</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>26</td>
<td>Unpleasant sensations in your legs at night or while resting, and a feeling that you need to move</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>27</td>
<td>Swelling of the legs</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>28</td>
<td>Excessive sweating</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>29</td>
<td>Double vision</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>30</td>
<td>Believing things are happening to you that other people say are not</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

All the information you supply through this form will be treated with confidence and will only be used for the purpose for which it has been collected. Information supplied will be used for monitoring purposes. Your personal data will be processed and held in accordance with the Data Protection Act 1998. Developed and validated by the International PD Non Motor Group.
**Functional Independence Measure Self Report (FIM-SR)**
(Modified from Grey & Kennedy, 1993; Masedo et al., 2005)

Please rate your level of independence on a variety of daily activities using a 1-7 scale:

7 = Complete independence (fully independent)
6 = Modified independence (requiring the use of a device but no physical help)
5 = Supervision (requiring only standby assistance or verbal prompting or help with set-up)
4 = Minimal assistance (requiring incidental hands-on help only; perform >75% of the task)
3 = Moderate assistance (perform 50-75% of the task)
2 = Maximal assistance (perform 25-49% of the task)
1 = Total assistance (perform 0-25% of the task)

**Self Care**
Eating
Grooming
Bathing/Showering
Dressing upper body
Dressing lower body
Toileting

**Sphincters**
Bladder management
Bowel management

**Mobility**
Transfers: bed/chair/wheelchair
Transfers: toilet
Transfers: bathtub/shower

**Locomotion**
Locomotion: walking/wheelchair
Locomotion: stairs

**Communication**
Expression
Comprehension

**Social Cognition**
Social interaction
Problem solving
Memory
### Starkstein Apathy Scale

#### Apathy Scale

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

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

(Starkstein et al., 1995)
**Parkinson’s Disease Questionnaire (PDQ-39) (Jenkinson et al., 2008)**

**DUE TO HAVING PARKINSON’S DISEASE, how often have you experienced the following, during the last month?**

<table>
<thead>
<tr>
<th>Please tick one box for each question</th>
<th>Never</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always or cannot do at all</th>
</tr>
</thead>
</table>

1. **Had difficulty doing the leisure activities which you would like to do?**

2. **Had difficulty looking after your home, e.g. DIY, housework, cooking?**

3. **Had difficulty carrying bags of shopping?**

4. **Had problems walking half a mile?**

5. **Had problems walking 100 yards?**

6. **Had problems getting around the house as easily as you would like?**

7. **Had difficulty getting around in public?**

8. **Needed someone else to accompany you when you went out?**

9. **Felt frightened or worried about falling over in public?**

*Please check that you have ticked one box for each question before going on to the next page.*
**Due to having Parkinson’s disease, how often during the last month have you**

Please tick one box for each question

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>10. Been confined to the house more than you would like?</td>
<td></td>
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<tr>
<td>11. Had difficulty washing yourself?</td>
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<tr>
<td>12. Had difficulty dressing yourself?</td>
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<tr>
<td>13. Had problems doing up buttons or shoe laces?</td>
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<tr>
<td>14. Had problems writing clearly?</td>
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<tr>
<td>15. Had difficulty cutting up your food?</td>
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<tr>
<td>16. Had difficulty holding a drink without spilling it?</td>
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<tr>
<td>17. Felt depressed?</td>
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<tr>
<td>18. Felt isolated and lonely?</td>
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</tr>
</tbody>
</table>

*Please check that you have ticked one box for each question before going on to the next page*
Due to having Parkinson’s disease, how often during the last month have you .

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>19. Felt weepy or tearful?</td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>20. Felt angry or bitter?</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>21. Felt anxious?</td>
<td></td>
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<tr>
<td>22. Felt worried about your future?</td>
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<tr>
<td>23. Felt you had to conceal your Parkinson’s from people?</td>
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<td></td>
</tr>
<tr>
<td>24. Avoided situations which involve eating or drinking in public?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25. Felt embarrassed in public due to having Parkinson’s disease?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. Felt worried by other people’s reaction to you?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. Had problems with your close personal relationships?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please check that you have ticked one box for each question before going on to the next page.
**Due to having Parkinson’s disease, how often during the last month have you**

*Please tick one box for each question*

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>28. Lacked support in the ways you need from your spouse or partner? <em>If you do not have a spouse or partner tick here.</em></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. Lacked support in the ways you need from your family or close friends?</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>30. Unexpectedly fallen asleep during the day?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>31. Had problems with your concentration, e.g. when reading or watching TV?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>32. Felt your memory was bad?</td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>33. Had distressing dreams or hallucinations?</td>
<td></td>
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</tr>
<tr>
<td>34. Had difficulty with your speech?</td>
<td></td>
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<tr>
<td>35. Felt unable to communicate with people properly?</td>
<td></td>
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</tr>
<tr>
<td>36. Felt ignored by people?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Please check that you have ticked one box for each question before going on to the next page*
Due to having Parkinson’s disease, how often during the last month have you...

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>37. Had painful muscle cramps or spasms?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>38. Had aches and pains in your joints or body?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>39. Felt unpleasantly hot or cold?</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Please check that you have ticked one box for each question

Thank you for completing the questionnaire
Revised Life Orientation Test (LOT-R) (Scheier, Carver, & Bridges, 1994)

Please be as honest and accurate as you can throughout. Try not to let your response to one statement influence your responses to other statements. There are no "correct" or "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer.

1. (O) In uncertain times, I usually expect the best.

   A
   I agree a lot

   B
   I agree a little

   C
   I neither agree nor disagree

   D
   I disagree a little

   E
   I disagree a lot

2. It's easy for me to relax.*

   A
   I agree a lot

   B
   I agree a little

   C
   I neither agree nor disagree

   D
   I disagree a little

   E
   I disagree a lot

3. (P) If something can go wrong for me, it will.

   A
   I agree a lot

   B
   I agree a little

   C
   I neither agree nor disagree

   D
   I disagree a little

   E
   I disagree a lot

4. (O) I'm always optimistic about my future.

   A
   I agree a lot

   B
   I agree a little

   C
   I neither agree nor disagree

   D
   I disagree a little

   E
   I disagree a lot

5. I enjoy my friends a lot.*

   A
   I agree a lot

   B
   I agree a little

   C
   I neither agree nor disagree

   D
   I disagree a little

   E
   I disagree a lot

6. It's important for me to keep busy.*

   A
   I agree a lot

   B
   I agree a little

   C
   I neither agree nor disagree

   D
   I disagree a little

   E
   I disagree a lot

7. (P) I hardly ever expect things to go my way.

   A
   I agree a lot

   B
   I agree a little

   C
   I neither agree nor disagree

   D
   I disagree a little

   E
   I disagree a lot
8. I don't get upset too easily.*

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I agree a lot</td>
<td>I agree a little</td>
<td>I neither agree nor disagree</td>
<td>I disagree a little</td>
<td>I disagree a lot</td>
</tr>
</tbody>
</table>

9. (P) I rarely count on good things happening to me.

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I agree a lot</td>
<td>I agree a little</td>
<td>I neither agree nor disagree</td>
<td>I disagree a little</td>
<td>I disagree a lot</td>
</tr>
</tbody>
</table>

10. (O) Overall, I expect more good things to happen to me than bad.

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
</tr>
</thead>
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<tr>
<td></td>
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<td>I agree a little</td>
<td>I neither agree nor disagree</td>
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<td>I disagree a lot</td>
</tr>
</tbody>
</table>

* Items 2, 5, 6, and 8 are filler items. O = optimism, P = pessimism
Beck Depression Inventory II (Beck, Steer, & Brown, 1996)

Instructions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the one statement in each group that best describes the way you have been feeling during the past two weeks, including today. Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

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 most 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
0 I have not experienced any change in my sleeping pattern.
1a I sleep somewhat more than usual.
1b I sleep somewhat less than usual.
2a I sleep a lot more than usual.
2b I sleep a lot less than usual.
3a I sleep most of the day.
3b I wake up 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.
1a My appetite is somewhat less than usual.
1b My appetite is somewhat greater than usual.
2a My appetite is much less than before.
2b My appetite is much greater than usual.
3a I have no appetite at all.
3b I crave food all the time.

19. Concentration Difficulty
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
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.

NOTICE: The form is printed with blue ink. If your copy does not appear the way it has been photocopied in whatever circumstances.
Satisfaction with Life Scale (Diener et al., 1985)

Instructions:
Below are five statements with which you may agree or disagree. Using the 1-7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.

The 7-point scale is:

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Slightly disagree</td>
<td>Neither agree nor disagree</td>
<td>Slightly agree</td>
<td>Agree</td>
<td>Strongly agree</td>
</tr>
</tbody>
</table>

_______ 1. In most ways my life is close to my ideal.

_______ 2. The conditions of my life are excellent

_______ 3. I am satisfied with my life.

_______ 4. So far I have gotten the important things I want in life.

_______ 5. If I could live my life over, I would change almost nothing.
Andrea Meryl Garroway was born on October 2, 1987, in Rochester, NY, and is an American citizen. She graduated from Brighton High School, Rochester, NY in 2005. She received her Bachelor of Science in Human Development from Cornell University, Ithaca, NY in 2009. She subsequently enrolled in a Clinical Psychology PhD graduate program at Virginia Commonwealth University, with a specialized emphasis on Behavioral Medicine. She received a Master of Science in Clinical Psychology from Virginia Commonwealth University in 2011.