

PATIENT-CAREGIVER ADJUSTMENT TO PARKINSON'S DISEASE:
A DYADIC INVESTIGATION

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ABSTRACT

Parkinson's disease (PD) is a common neurodegenerative disorder affecting cognitive and motor functioning. The progressive nature of PD makes it a difficult disease for not only patients, but also their primary caregivers to cope with. There is evidence suggesting additional influences of social interactions to the psychological functioning of patients and caregivers in these patient- caregiver dyads, with the nature of perceived social interactions being associated to patient and caregiver outcomes. The current paper reports the relationship between supportive and unsupportive dyadic exchanges in 30 PD-MCI patients and their spousal caregivers, and how this was related to psychological functioning (psychological well-being and perceived relationship quality) of both spouses. Bivariate analyses suggested high levels of agreement in terms of how patients and caregivers perceived social interactions and their relationship quality, with patients and caregivers reporting high relationship quality and low levels of psychological distress. Furthermore, actor-partner-interdependence models (APIM), as predicted, revealed significant actor and partner effects between social interaction variables and psychological functioning, for both patients and caregivers, suggesting that social interactions from one spouse, influenced not only their own psychological functioning, but also their spouses'. These results further add to the general relationship and health literature that social interactions are related to psychological well-being and relationship quality in dyads adjusting to chronic illness. Furthermore, this is the first study to report dyadic interactions of this nature in PD-MCI patient-caregiver dyads, and warrants further longitudinal investigation to investigate the cause and effect of these associations.

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1 INTRODUCTION

1.1 Overview

Parkinson's disease (PD) is a common neurodegenerative disorder affecting motor and cognitive functioning (Tew, Naismith, Pereira & Lewis, 2013; Leiknes, Tsynes, Aarsland, Larsen, 2010; Aarsland et al, 2007). The progressive and unpredictable nature of PD makes it a difficult disorder to cope with, both for patients and their primary caregivers, influencing the psychological functioning of both (Janvin, Aarsland & Larsen, 2005; Schrag, Hovris, Morley, Quin & Jahanshahi, 2006). Indeed, research has shown that symptoms of anxiety and depression are common in both patients and their caregivers (who may also report symptoms of caregiver burden) (Martinez-Martin et al, 2007; Schneider, Althaus, Backes & Dodel, 2008; Aarsland et al, 2009; Lee, Tsai, Gauthier, Wang & Fuh, 2012). Research examining predictors of psychological functioning in PD patients and their caregivers has mostly focused on disease-related variables, showing that cognitive impairment in particular is a strong predictor of negative psychological outcomes in patients and caregivers (Ryan et al, 2012).

Not all cognitively impaired patients and their caregivers experience negative psychological outcomes however, suggesting the need to examine non-cognitive variables. One important variable to consider may be the quality of interactions between patient and caregiver. In this thesis I will examine the relation between supportive and unsupportive dyadic exchanges (i.e., between patient and caregiver) and psychological functioning of both patients and caregivers. Beyond the frequently measured variables of anxiety, depression and caregiver burden, this thesis also examined perceived relationship quality as an indicator of psychological well-being. To avoid problems inherent in dementia patients, yet focus on those whose cognition shows signs of impairment, these relationships were examined in a relatively homogenous sample of patients who have all been characterized as showing PD

with mild cognitive impairment (PD-MCI) using well-validated international criteria (Litvan et al, 2012; Wood et al, 2016).

The following sections describe PD-MCI, followed by relationships between cognitive impairment, psychological well-being, social interactions and relationship quality in general terms as well as in the context of PD.

1.2 Parkinson's disease and mild cognitive impairment

PD is a severe neurodegenerative disorder that causes deterioration of patient's functional and psychosocial status (Tew et al, 2013; Leiknes et al, 2010; Aarsland et al, 2007; Martinez-Martin et al, 2008). The cognitive and behavioural symptoms in PD relate to deficiencies in serotonergic, noradrenergic and cholinergic neurotransmission, in addition to dopaminergic decline and neuropathological changes across many brain systems (Braak et al, 2003). In New Zealand, around 10,000 individuals live with PD (www.parkinsons.org.nz) and this is predicted to increase due to an ageing population.

Research has shown that PD results in dementia for approximately 80% of patients (Rongve & Aarsland, 2006), and PD cognition is divided into three stages (Dalrymple et al, 2011; Wood et al, 2016). PD patients who show no clinically significant cognitive impairment are classified as PD unimpaired (PD-N), patients who show mild cognitive impairment but no interference to executive function are classified as PD-MCI, and PD patients that have progressed to dementia, who show significant interference in functional independence and executive function are classified as PD-D (McKeith & Mosimann, 2004).

According to the Movement Disorders Society (MDS) Task Force proposal (Litvan et al, 2012), PD-MCI is a syndrome defined by three sets of criteria; namely clinical, cognitive and functional. The MDS guidelines for inclusion and exclusion criteria for PD-MCI comprise of two levels of assessment (Litvan et al, 2012). Level 1 criteria consists of a brief assessment demonstrating impairment on global cognitive tests or impairment on 1 or 2 tests

in less than 5 different cognitive domains (attention and working memory, executive function, language, memory and visuospatial function). Level 2 criteria, a more comprehensive assessment than Level 1, requires assessment of at least 2 tests within each of the 5 cognitive domains. Both levels of assessment require cognitive decline with impairments not interfering significantly with functional independence (Litvan et al, 2012). MCI occurs in about 25-30% of PD patients and studies have shown that those identified with MCI are at an increased risk for dementia within 4 years (Aarsland et al, 2010; Dalrymple-Alford et al, 2011; Pedersen et al, 2013; Wood et al, 2016). Factors that contribute to PD-MCI include older age at disease onset, being male, severity of motor symptoms, depression and advanced disease stage (Leroi et al, 2012).

The current study focuses on PD-MCI, due to the limited research available that outlines the specific impacts that PD-MCI may have on patients, and also their caregivers (Leroi et al, 2012). Moreover, little is known about the influences PD-MCI may have on psychological well-being and relationship functioning in dyads.

1.3 Cognitive impairment, psychological and relationship functioning.

Ageing populations are creating a higher prevalence of age-related neurodegenerative disorders and chronic illness and thus, an increased burden on carers and increased demand for health care services (Cornwall & Davey, 2004). There has been a lot of research focusing on the link between cognitive functioning and patient outcomes; and the past couple of decades has given rise to a lot more research surrounding caregiver outcomes also (albeit less in PD samples). However, there is a lot less research examining how cognition influences relationship outcomes for both patients and caregivers. The following sections outline the impacts of cognition on patient psychological functioning, followed by caregiver psychological functioning and relationship functioning for both patients and caregivers.

1.3.1 Cognitive Functioning and Patient Psychological Functioning

There is a great deal of research examining the impact of cognitive impairment on psychological functioning and this research shows that depression and anxiety are common, and frequently co-morbid in patients with PD (Connolly & Fox, 2014; Landau et al, 2016; Wee et al, 2016). Mood disorders, such as anxiety and depression, have been found to predate motor symptoms in PD, and can be an early indicator of the disease (Connolly & Fox, 2014). For example, a recent study (Landau et al, 2016) investigating depression and anxiety in PD patients over a 4-year period found that anxiety was present in 20% of patients, and 50% of these patients had co-occurring depressive symptoms. The levels of depression and anxiety found in the patients in Landau's study remained stable over the 4-year period and anxiety, whether depression was present or not, appeared to be the prominent psychopathological phenotype in PD in this sample. Consistent with these findings, Wee and colleagues (2016) examined the longitudinal course and determinants of depression and anxiety in PD patients using the Geriatric Depression Scale (GDS-15) and Hospital Anxiety and Depression Anxiety Subscale (HADS-A). Prevalence rates of depression and anxiety were 34.8% and 21.3%, respectively, and were comorbid in 13.5% of the patients assessed; depressive symptoms remained stable over the 18 months whilst anxiety improved. Wee and others indicated that depressive symptoms found in patients were associated with female gender, motor fluctuations, apathy and anxiety. Conversely, anxiety symptoms were found to be related to older age, higher educational attainment, shorter disease duration and younger age of disease onset. Although co-morbid, this and other studies (Landau et al, 2016) show that anxiety and depression are dissociable from each other in patients and are influenced by different factors.

These findings are consistent with previous work conducted by Meara and others (1999) and Dissanyaka and colleagues (2011) who assessed levels of depression in PD patients. Meara et al (1999) and Dissanyaka et al (2011) found 64% and 66% of patients,

respectively, scored within the depressed range on the 15-item Geriatric Depression Scale (GDS-15). Patients with high levels of depressive symptoms tended to have more severe disease symptomatology, longer disease duration and greater cognitive impairment.

Dissanyaka and colleagues (2011) also reported that PD patients with depression were more likely to have co-morbid anxiety.

1.3.2 Cognitive Functioning and Caregiver Psychological Functioning

Long term illness caregiving in progressive diseases such as dementia, Alzheimer's disease (AD), PD, and other chronic illnesses has been correlated with a number of negative psychological, emotional and social problems for the caregiving individual (Shim, Landerman & Davis, 2011). Caregiver burden, the construct that integrates these problems, is a complex concept linked to external factors that are determined by the patient (e.g., disability), the environment (e.g. interactions) and personal characteristics (e.g., coping) (Martinez-Martin et al, 2008).

Research findings surrounding the influence of cognitive impairment on caregiver burden indicate negative outcomes for caregivers, as the frequently co-morbid psychological complaints associated with PD contribute to overall feelings of caregiver burden (Martinez-Martin et al, 2007; Connolly & Fox, 2014; Coony & Stacy, 2016; Wee et al, 2016). Aarsland and colleagues (1999) and Martinez-Martin and colleagues (2007) examined the impact of patient cognitive status, neuropsychiatric and motor symptoms on caregiver outcomes and found significant associations between these variables and negative outcomes for the caregivers. The study by Meara et al (1999) also investigated the caregivers of PD patients and found that 34% of carers scored within the depressed range on the 15-item Geriatric Depression Scale (GDS-15). Moreover, a study examining the effects of everyday stressors associated with non-PD MCI on the psychological well-being of non-PD MCI patients spouses' revealed that changes in psychological affect (depressive symptoms) were predicted

by cognition and behavioural problems associated with memory deficits (Savla, Blieszner, Cox & Gwazdauskas, 2011). Furthermore, Stinson and others (2014) evaluated correlations between neuropsychological test performance of non-PD veteran patients and caregiver burden and reported that performance in memory, attention, processing speed, executive functioning and emotional functioning domains were solely related to the caregiver dependency burden factor of the Zarit Burden Interview (ZBI), not the domains of guilt or psychosocial burden that Stinson and colleagues identified from principal components analyses of the ZBI (ZBI; Zarit, Reever & Bach-Peterson, 1980). Severity of cognitive impairment was found to further influence levels of reported caregiver burden (Stinson et al, 2014).

Ryan and colleagues (2012) investigated the impact of no cognitive impairment, non-PD MCI and AD on caregivers in terms of neuropsychiatric problems and burden and found that caregivers of MCI patients reported significantly higher burden than those individuals than no cognitive impairment, but less than AD caregivers. MCI caregivers also reported greater burden when neuropsychiatric and executive functioning were lower in patients. Recently, Paradise and colleagues (2015) compared burden in caregivers of patients with MCI compared to healthy controls and found that 36% of MCI caregivers reported clinically significant levels of burden, twice that of healthy controls. Patient depression and cognition were found to have a significant association with reported burden, due to the assumption that caring for an individual with MCI shares characteristics with dementia caregiving (Paradise et al, 2015).

Although research has found significant associations between cognition in PD patient and caregiver burden, there are studies that do not support this. Patient non-motor psychological symptoms, for example, have been found to have greater impact on caregiver burden and psychological functioning than motor symptoms (Carter, Stewart, Lyons &

Archbold, 2008). Furthermore, Rosdinom and colleagues (2013) examined the relationships between behavioural and psychological symptoms of dementia, cognitive impairment and caregiver burden and found that cognitive impairment did not contribute to caregiver burden. Instead, it was gender and behavioural symptoms of dementia that were associated with higher burden. Consistent with these findings, a meta-analysis examining the correlates of caregiver distress in 10 studies investigating PD (Lau & Au, 2011) concluded that motor symptoms had the strongest relationship with caregiver burden and depression. There was however, a significant correlation for cognition ($r = .28$), but the size of the motor symptom correlation was greater ($r = .42$). Thus, the impact of PD patient cognition on caregiver outcomes is not clear, and somewhat inconsistent, and requires further investigation.

1.3.3 Cognitive Functioning and Relationship Functioning

Although ample research has examined the link between cognitive impairment and psychological functioning of patients and their caregivers, much less research has examined the influence of cognitive impairment on relationship outcomes. The research that has been conducted largely indicates negative impacts on relationship functioning when one individual is cognitively impaired, and often only reports individual outcomes for patients or caregivers. There are studies however, that have investigated the influence of cognitive impairment and PD on relationship outcomes in couples and findings are mixed in terms of whether negative outcomes are influenced by cognition, or whether other disease or non-cognitive factors, such as depression or anxiety, play a role. Blieszner and colleagues (2007) investigated the concept of ambiguous loss in couples with non-PD MCI. Interviews with 67 couples revealed that the lack of understanding about MCI resulted in a great deal of ambiguity in their lives, and as a result, couples often experienced distress that affected their emotional involvement with each other and thus, relationship quality. Consistent with the findings of Blieszner et al (2007), a study examining spouses and changes related to MCI found that the greater the

level of cognitive impairment found in both partners, the more changes to interactions and relationship quality occurred (Roberto, McCann & Blieszner, 2011). A study examining the behavioural changes associated with dementia and the effect on relationship quality found that new behaviours, typically reflecting disturbed elements of communication, were distressing for caregivers and influenced their ratings of relationship quality. Furthermore, this study found that when non-PD MCI patients talked little or not at all, or when repetition of questions and statements occurred, the spouse reported lower levels of marital relationship satisfaction, showing that cognition had a negative influence on relationship functioning (Garand et al, 2007). Research conducted by Davies and others (2010) examined issues of intimacy and relationship functioning in spousal caregivers of dementia and non-PD MCI patients. Both groups reported difficulty in anticipating the future of their relationships due to the present stressors and the authors suggested that earlier intervention for both individuals in this sample may maintain relationship satisfaction. de Vugt and colleagues (2013) also examined problems associated with dementia and its effects on marital relationship satisfaction. In this study, caregivers reported deterioration of their relationship, yet also reported feeling closer to their spouse. Apathy, but not depression, was a significant predictor of deterioration of relationship quality. Behavioural problems associated with dementia were independent of patient cognitive status and were associated with deterioration in relationship quality for both patients and caregivers, indicating that cognitive impairment was not related to relationship quality. A review conducted by Quinn, Clare and Woods (2009) investigated relationship quality in terms of well-being in dementia caregivers. Findings from this review showed that caregiving has an impact on the quality of the relationship between caregiver and patient. Quinn, Clare and Woods (2009) further suggested that caregiving for cognitively impaired spouses results in role change and thus, influences relationship quality. Furthermore, Xu and colleagues (2016) recently examined the associations between marital

quality and change in cognition in late life and found that more frequent negative marital experiences were associated with an increase in cognitive limitations over time, and this association was found to be similar for both men and women. McCarthey, Lyons and Powers (2012) examined the effects of relationship quality and depressive symptoms in stroke-survivor dyads and consistent with previously mentioned studies, found that lower perceived relationship quality for both patient and spouse was strongly associated with greater depressive symptomatology.

The findings of previous research discussed in this section outline the negative impacts cognitive impairment have on the psychological and relationship functioning of patients and caregivers. Research has found frequent co-morbidity of anxiety and depression in individuals with cognitive impairment and PD patients; and these psychological complaints influencing caregiver burden. Studies have generally focused on individual outcomes and have not assessed patients and caregivers together, which is important to consider due to the bidirectional influences of patient health and caregiver health (Mavandadi et al, 2014). Considering the influence of these factors, change in an individual and how they feel about their relationships with others cannot be understood without examining the social context within which the individual is embedded (Lyons, Sayer, Archbold, Hornbrook & Stewart, 2007).

1.4 Social interactions, psychological and relationship functioning

Social well-being is a consequence of the interrelationship of physical, psychological and social influences experienced by individuals (Newsom, Nishishiba, Morgan & Rook, 2003; Porter & Oliva, 2007). These social relationships are shaped in networks of support and exchanges, formed by people who supply emotional support, companionship, instrumental help and advice. Networks of support relate to quality of life and social well-being, and are directly influenced by the number of stressors and resources that a person possesses

(Newsom et al, 2003; Karademas, 2014). Social interactions from these networks can manifest in a variety of ways and are either positive or negative for the individuals involved, and research has shown that these positive and negative social interactions have profound impacts on socio-emotional well-being. These positive and negative interactions become especially important when chronic illness arises (Kroerner, Kenyon & Shirai, 2009; Mavandadi, Rook, & Newsom, 2007; Karantzas & Gillath, In Press). In turn, changes in health status as one ages can also exert influence on an individual's social support networks and can therefore influence disease progression and social well-being (Porter & Oliva, 2007).

Social interactions within the patient-caregiver dyad, therefore, contribute to the psychological well-being and relationship quality of both patients and caregivers (Lyons et al, 2002). Interactions between patients and their caregivers, in particular, may be fundamental for the adjustment and well-being of both partners (Karademas, 2014). These interactions can influence how couples cope with the stressors associated with chronic illness (Newsom et al, 2005; Karantzas & Gillath, In Press). For example, patients and caregivers who perceive their social interactions as negative are more likely to report feelings of depression and anxiety (Ricciardi et al, 2015). Moreover, social interactions can influence relationship quality. Higher levels of negative interactions in couples influence the perception of relationship quality in both individuals (O'Connor et al, 2008).

Dyadic coping is another concept related to social well-being, and assumes interdependence of spouses, common concerns and mutual goals in the face of a stressor (Bodenmann, 1997; Revenson, Kayser & Bodenmann, 2007). Dyadic coping is especially important in patient-caregiver relationships (Bodenmann, 1997) and there is a variety of ways that couples or caregivers in a patient-caregiver dyad potentially interact (e.g environment, support, collaboration, protective buffering, and active engagement etcetera) as they manage stressors (Checton, Magsamen-Conrad, Ventis & Greene, 2015). Mutuality, defined as the

quality of interaction or reciprocity of sentiment in a relationship (Tanji et al, 2008; Shim, Landerman & Davis, 2011), is an important component of dyadic coping and has been associated with patient and caregiver outcomes. For example, higher levels of mutuality in relationships has been associated with lower levels of caregiver burden and psychological complaints in both PD patients and caregivers and influences perceived positive and negative social interactions in dyads (Archbold, Stewart, Greenlick & Harvarth, 1990; Tanji et al, 2008; Lyons et al, 2009; Shim, Landerman & Davis, 2011).

Throughout the chronic illness literature, it is widely accepted that positive social interactions help to buffer stress, enhance psychological wellbeing and can mitigate declines in health (Feeney & Collins, 2003; Mavandadi et al, 2007; Newsom, Rook, Nishishiba, Sorkin & Mahan, 2005; Rook; 2015). Caregivers of individuals who are chronically ill are faced with daily challenges, which are achieved with greater efficacy and satisfaction if they received support from others (Melrose, Brown & Wood, 2015). A study investigated whether the impact of negative and positive social interactions on depression depended on the type of relationship among late-middle aged and older adults. This study found that negative, but not positive, social exchanges with other family and friends was independently related to depression. The association between depression and positive and negative social interactions in this study was weaker among individuals that were aged 70 years and older, compared to those aged 50-70 (Stafford et al, 2011). How patients and caregivers perceive the quality of social support they receive, is an important predictor of carer distress, marital satisfaction and patient quality of life (Pagninia et al, 2010). Rapp and colleagues (1998) assessed caregivers of persons living with dementia and found that perceived levels of social support by the caregiver was significantly related to caregiver outcomes in terms of patient cognition and behaviour problems. Lakey and colleagues (2002) assessed 100 daughter caregivers of patients with probable. Caregivers who perceived their social network as more supportive

were in better psychological and physical health than those who judged their social support networks as less favourable (Lahey et al, 2002). Similarly, Jeongim (2014) recently examined the relationship between religious coping, positive aspects of caregiving, perceived social support and caregiver burden in AD caregivers and found that positive aspects of caregiving and religious coping were associated with lower levels of burden in AD caregivers.

Social interactions in chronic illness influence relationship functioning, and this is even more the case in spousal pairs. O'Connor and colleagues (2008) examined the marital relationships in patients and caregivers coping with Motor Neurone disease (MND), Huntington's disease (HD), PD and multiple sclerosis (MS). Results from this study revealed that carers of those with HD had significantly lower levels of relationship satisfaction than the other illness groups, and social support was found to predict marital satisfaction in patients with PD, MS and MND. Carers of PD patients reported significantly lower relationship satisfaction than patients, and this was found for carers of MS and MND patients also. Consistent with the findings of O'Connor and colleagues, Savla et al (2011) also found that positive and negative marital relationship interactions predicted changes in psychological affect (depressive symptoms) in caregivers of patients with non-PD MCI. Furthermore, Karademas (2014) investigated the influence of illness cognitions on the psychological well-being of chronically ill patients with cardiovascular disease and their spouses; cross-over effects between how both patients and caregivers perceived the illness and how this influenced the psychological well-being of their partner were found, indicating that how patients and caregivers adjust to chronic illness affects the psychological well-being of their partner. However, these relationships were not significant when higher levels of relationship quality were reported, which is further in line with previous research indicating that higher levels of positive interactions and relationship quality reduces psychological distress (Newsom et al, 2005; Mavandadi et al, 2007; Pagninia et al, 2010).

Caregiving is widely acknowledged as being a source of physical, psychological and social burden that affects well-being in terms of relationship quality and psychological functioning (Rapp et al, 1998; Neri et al, 2012). Research conducted by Simpson and colleagues (2006) explored the relationship between social support and physical functioning in patients with idiopathic PD and found that the less satisfaction with social support an individual reported, the higher their psychological distress.

Relationship mutuality (quality of interaction or reciprocity of sentiment in a relationship) is also an important component of social interactions in patient-caregiver dyads. For example, Lyons and colleagues (2007) found that older caregivers reported higher levels of mutuality than did younger family caregivers, but this mutuality declined over time. Lyons et al (2007) also found that higher levels of patient depression were associated with lower levels of mutuality. The change in mutuality that was reported in this study for caregivers was related to levels of depression. A dyadic “crossover” effect was also found in this study, with the average health of the older adult being negatively associated with mutuality in their family caregiver.

To the best of our knowledge, only 6 studies to date touch on dyadic interactions in PD in terms of the relationship quality and social interactions. Due to the bidirectional influences of changes in both physical and cognitive functioning in PD patients, the potential of strain on social relationships and interpersonal stress is high and increases not only personal stress but interpersonal stress as well (Mavandadi et al, 2014). A study conducted by Thommessen and colleagues (2002) investigated dyads with stroke, mild dementia and PD found that lower cognitive function of the patient was associated with higher levels of psychosocial burden on spouses of patients with stroke and PD. Higher amounts of burden were reported by those in a spousal relationship with PD patients (Thommessen et al, 2002).

Tanji and others (2008) assessed the association between mutuality and the marital relationship in 96 PD patient-spouse pairs. Higher levels of mutuality, as reported by the spouse, was associated with less caregiver burden, less depression for both patient and caregiver and less PD severity. Mutuality was also inversely associated with motor fluctuations; with higher mutuality found to be associated with fewer motor fluctuations for the patient. Greater mutuality between patients and spouses was associated with better psychological functioning of both partners and reduced caregiver burden. A study conducted by Shim, Landerman and Davis (2011) further investigated correlates of care relationship mutuality in caregiver's of AD and PD patients and found that mutuality was significantly related to patient functional ability, caregiver depressive symptoms and duration of caregiving. Higher mutuality for PD patients was associated with less disease severity, less caregiver burden and less depression for both individuals

Mavandadi and colleagues (2014) investigated the association of benefit finding (the experience of personal growth) in the face of a stressor (PD) and perceived marital quality in 25 married couples. Mavandadi et al found greater perceived benefits from having PD or living with a spouse with PD was associated with greater marital quality for both individuals. Ricciardi et al (2015) examined emotional awareness, relationship quality and satisfaction in 15 spousal dyads where one individual had PD. Ricciardi and colleagues found that patients were significantly less satisfied than their partners and were more depressed and anxious. There was a negative correlation between measures of relationship quality, satisfaction and emotional awareness for patients; no correlations were found between relationship quality and satisfaction in either patients or caregivers. It was concluded that anxiety and satisfaction were significant predictors of how patients evaluated their social support and interactions. These findings were also consistent with the findings of O'Connor and colleagues (2008) who reported that patients and caregivers perceptions of social support influenced their

individual ratings of relationship quality. Finally, Szeto and colleagues (2016) more recently investigated caregiver outcomes in PD-N versus PD-MCI patients in terms of quality of life and found no significant difference in terms of psychological status, social interactions and anxiety and depression.

The findings in this section have outlined the importance of social interactions in dyads facing chronic illness, and how these interactions can influence psychological well-being and relationship quality for both individuals. Positive and negative interactions, and mutuality, influence relationship quality and feelings of depression and anxiety in patients and caregivers facing PD and MCI. Further exploration of these factors is needed however.

1.5 Rationale for the current study

To the best of my knowledge, the relation between supportive and unsupportive dyadic exchanges (i.e., between patient and caregiver) and psychological well-being (psychological functioning and perceived relationship quality) in PD-MCI patients and their caregivers has not yet been investigated. Research examining predictors of psychological functioning in PD patients and their caregivers has mostly focused on disease related variables. Other variables (such as social interaction variables) have received much less attention. Very few studies have looked at social interactions, marital quality and psychological well-being in PD patient-caregiver *dyads* (for exceptions, see previous sections). The caregiving relationship, by definition, is made up of two individuals and couples generally respond to illness as a social unit (Pakenham, 1998). The levels of strain and congruence within this relationship interact and contribute to the well-being of both individuals (Lyons et al, 2002; Braun et al, 2009). Thus, how one individual thinks, feels or behaves may not only effect their own well-being, but also their partner's well-being. For example, both Shim et al (2011) and Tanji et al (2008) found that greater mutuality in the relationship as perceived by patients, was related to better psychological functioning of *both*

spouses (i.e., patient and caregiving spouse). In the relationship literature, these effects are commonly referred to as *actor* effects (the relation between one person's score on a predictor variable and their own score on an outcome variable) and *partner* effects (the relation between one person's score on a predictor variable and their partner's score on an outcome variable) (Kenny and Cook, 1999; Korporaal et al, 2013; Checton et al, 2015). In the current study, both actor and partner effects will be examined; this has only been done once previously in PD patients and their spouses (c.f. Mavandadi et al, 2014).

No studies to date have examined the impact of MCI in PD on the quality of social interactions, using measures such as the positive and negative social exchanges scale (Newsom et al, 2005) and the Mutuality Scale (Archbold et al, 1990), and relationship quality, using measures such as the Relationship Assessment Scale (Hendrick, 1988) on psychological wellbeing in patient-spouse dyads. Leroi and colleagues (2012) signaled a need for studies aimed at identification and intervention in PD-MCI, due to the limited research available that investigates the impacts beyond cognition in PD-MCI, which may have further influence on patients and caregivers. Jones (2013) was the first study that identified significant differences between caregivers of patients with PD-N, PD-MCI and PD-D in terms of caregiver burden; with caregivers of PD-MCI patients reporting significantly higher levels of burden than caregivers of PD-N patients.

The main aim of the current study was to investigate the relationship between supportive and unsupportive dyadic interactions and indicators of psychological well-being (anxiety, depression, relationship satisfaction, and for caregivers only, caregiver burden) in PD-MCI patient-caregiver dyads. Associations between neuropsychological variables, social interaction variables and indicators of psychological well-being were also examined. Based on the literature reviewed above, I formulated the following hypotheses:

- 1) Higher levels of patient clinical and cognitive impairment will be related to lower levels of psychological well-being in patients and their caregivers. The associations with supportive and unsupportive dyadic interactions will be explored.
- 2) Patients' and caregivers' perceptions of supportive and unsupportive interactions in their relationship will be related to their *own* psychological well-being (actor effects). That is, patients and caregivers who report more positive interactions, fewer negative interactions and greater mutuality in their relationship, will report higher levels of psychological well-being.
- 3) Patients' and caregivers' perceptions of supportive and unsupportive interactions in their relationship will be related to the *other person's* (i.e. *their partner's*) psychological well-being (partner effects). That is, patients and caregivers who report more positive interactions, fewer negative interactions and greater mutuality in their relationship, will have partners who report higher levels of psychological well-being.

2 METHOD

2.1 Overview

The current study employed a dyadic nested design to examine the relationship between support exchanges, relationship quality and indicators of well-being in PD-MCI patients and their caregivers. Ethical approval for this investigation was given by the Southern Health and Disability Ethics Committee (Reference URB/09/08/037/AM11) and all participants gave informed consent. Copies of the information sheets and consent forms given to both Parkinson's disease patients and their primary caregivers are included in Appendix A.

2.2 Participants

PD patients were identified from a database of volunteers at the New Zealand Brain Research Institute (NZBRI) in Christchurch, and met the UK Parkinson's Disease Society's criteria for idiopathic Parkinson's disease (See Appendix A). To be eligible to participate in the current study, patients had to be classified as PD-MCI meeting Level 2 criteria proposed by the MDS (see 'patient neuropsychological assessment' for MCI criteria) and to have a significant other willing to participate in the study. The significant other did not have to share a household with the patient. Thirty-seven eligible dyads were contacted to participate. Of the 37 dyads contacted, six declined to participate for the following reasons: the recent ending of the long-term spousal relationship (n=1), additional health problems (n=4) and not wanting to drive in the city anymore (n=1). The thirty-one remaining dyads were interviewed at the NZBRI. Only one of these dyad's involved a non-spouse caregiver, so this dyad was not included in the final analyses.

2.3 Clinical and Neuropsychological Assessments

Five cognitive domains (executive function; language; visuospatial; attention and working memory/processing speed; and episodic memory) were assessed in two neuropsychological assessments prior to interviews (per Wood et al., 2016, Dalrymple-Alford et al., 2011).

Executive function was assessed using the Stroop interference test, letter fluency, category fluency and category switching (from the Delis-Kaplan Executive Function System, Delis, Kaplan & Kramer, 2001), and action fluency and Trails B. Language was assessed using the Boston Naming Test, the Dementia Rating Scale-2 similarities sub-test, and the language component of the Alzheimer's Dementia Assessment Cognitive Scale.

Visuospatial/Visuoperceptual performance was determined using the judgement of line orientation test (JOL), the fragmented letters test, the picture completion test and the Rey Complex Figure Test-Copy. Attention, Working Memory and Processing speed was evaluated using the digits forward/backwards test, the digit ordering test, the map search task (from the test of everyday attention), the Stroop colour reading test, the Stroop word reading test and Trails A. Episodic memory was measured using the California Verbal Language Test-II Short Form (CVLT) and the Rey Complex Figure Test; impairment in either or both delay components of each memory test counts as a single one impairment. Scoring of the neuropsychological tests employed age- and education adjusted normative data. A global cognitive Z score was calculated for each patient from four domains, by averaging the means of the average scores within each of four domains (language was excluded due to non-normality of the data).

As previously mentioned in Section 1.2, MDS Level 2 criteria for PD-MCI requires assessment of at least 2 tests in each of the 5 cognitive domains (attention and working memory, executive function, language, memory and visuospatial function). For the NZBRI criteria, this required impairment on at least 2 neuropsychological tests below -1.5 SD/7th

percentile within one of these cognitive domains. Patients meeting criteria for PD-MCI also did not show significant impairment in everyday function (based on the Reisberg ADL and Clinical Dementia Rating Scale).

Patients were also assessed on; the Montreal Cognitive Assessment (MoCA), a screening tool for cognitive impairment in PD (Dalrymple-Alford et al, 2010) and the WTAR (Wechsler Test of Adult Reading; to estimate premorbid intellectual functioning (IQ) (Mullen and Fouty, 2014). Patients also received the PD clinical test, the Universal Parkinson's Disease Rating Scale (UPDRS) (Part 1 assesses Non-Motor aspects of Experiences of Daily Living; Part 2 covers Motor Aspects of Experiences of Daily Living; and Part 3 comprises of a motor examination). In particular, patients in the current study performed worse in domains of Executive Function (Action Fluency and Trails B) and Attention, Working Memory and Processing Speed (Digit Ordering and the Map Search Task). A summary of all domain scores for PD-MCI patients is provided in Table 1.

Table 1. Neuropsychological assessment scores for PD-MCI patients

Neuropsychological Test Domains	PD-MCI Score Mean \pm SD n=30
Attention, Working Memory and Processing Speed	
Digits F/B	0.12 \pm 0.9
Digit Ordering	-1.42 \pm 1.0
TEA (Map Search)	-1.6 \pm 0.8
Stroop Colour	-0.80 \pm 0.9
Stroop Word	-0.38 \pm 0.9
Trails A	-.037 \pm 0.9
Domain Score	-0.74 \pm 0.4
Executive Function	
Letter Fluency	-0.27 \pm 1.9
Action Fluency	-1.47 \pm 0.9
Category Fluency	-0.57 \pm 0.9
Category Switching	-1.04 \pm 1.0
Trails B	-1.28 \pm 1.2
Stroop	-0.90 \pm 1.5
Domain Score	-0.92 \pm 0.5
Visuoperceptual/Visuospatial	
JOL	-0.57 \pm 1.0
VOSP	-0.12 \pm 0.9
Rey Copy	-1.32 \pm 1.0
Domain Score	-0.41 \pm 0.6
Learning and Memory (Episodic)	
CVLT Free Recall	-0.69 \pm 1.0
CVLT Short Delay	-0.88 \pm 1.1
Rey Immediate	-0.79 \pm 0.9
Rey Delayed	-1.06 \pm 1.1
Domain Score	-0.79 \pm 0.7
Global Neuropsychological Z Score	
MoCA	23.3 \pm 3.2
Premorbid IQ (WTAR)	109.4 \pm 9.2
Hoehn and Yahr Stage	2.36 \pm 0.6
UPDRS Part 1	11.83 \pm 4.8
UPDRS Part 2	14.7 \pm 6.0
UPDRS Part 3	37.3 \pm 12.7

CVLT Free Recall California Verbal Learning Test Free Recall; CVLT Short Delay California Verbal; Learning Test Short Delay; JOL Judgement of Line; Premorbid IQ (WTAR) Weschler Test of Adult Reading; TEA Map Search Test of Everyday Attention; UPDRS Universal Parkinson's Disease Rating Scale; VOSP Visual Object and Space Perception Battery.

2.4 Measures completed by both patients and caregivers

Patient-caregiver pairs (dyads) were interviewed at the NZBRI. Both patient and spouse were invited into an assessment room where a short video was taken of an interaction task (not included in this thesis). Following this, patient and spouse were separated and interviewed alone by the author (MM) and another researcher, to enable each participant to respond to questions about their spouse and their relationship in an unhindered way.

Relationship Satisfaction

Relationship satisfaction was measured using the 7 item Relationship Assessment Scale (RAS) (Hendrick, 1988). The scale is designed to test the level of overall satisfaction with romantic relationships of marital and non-marital nature (Villar & Villamizar, 2012). Respondents reported answers on a 5-point Likert scale ranging from 1 to 5, to questions such as “How well does your partner meet your needs”, “In general, how satisfied are you with your relationship?” and “How often do you wish you hadn’t gotten into this relationship?”. The RAS has been used extensively in relationship research and has good internal consistency with Cronbach’s alpha values of .83-.86 (e.g. Cramer, 2004; Villar & Villamizar, 2012). This scale showed good internal consistency in the current study with Cronbach’s alpha values of .88 for both patients and caregivers respectively.

Mutuality

Mutuality was measured with the 15-item Mutuality Scale (Archbold et al, 1990). The Mutuality Scale reflects the interactive nature of relationship quality, including dimensions of reciprocity (e.g. “how much does he or she express feelings of appreciation for you and the things that you do?”), love and affection (e.g. “how much love do you feel for him or her?”), shared pleasurable activities (e.g. how much do you enjoy sharing past experiences with him or her?”), and shared values (e.g. “to what extent do the two of you see eye to eye?”).

Responses to scale items were rated on a four point Likert scale ranging from 0 (not at all) to 4 (a great deal) (Archbold et al, 1990; Crist et al 2004; Lyons et al., 2007). The Mutuality scale has been used in dyadic research in PD (Lyons et al, 2009) and has good internal consistency with a Cronbach's alpha of .91-.95. Reliability of the Mutuality scale in the current study revealed Cronbach's alpha of .95 and .89 for patients and caregivers respectively.

Social Support

Positive and negative social exchanges were measured using the Positive and Negative Social Exchanges (PANSE) (Newsom et al, 2005). This 24 item scale was used to assess four domains of positive and negative social exchanges. The four positive domains are informational support (e.g. "how often in the past month did your spouse make useful suggestions?"), instrumental support (e.g. "how often in the past month did your spouse do favours and other things for you?"), emotional support (e.g. "how often in the past month did your spouse do or say things that were kind or considerate towards you?"), and companionship (e.g. "how often in the past month did your spouse do social or recreational activities with you?"). The four parallel negative domains are unwanted advice or intrusion (e.g. " how often in the past month did your spouse give you unwanted advice?"), failure to provide help (e.g. "how often in the past month did your spouse let you down when you needed help?"), unsympathetic or insensitive behavior (e.g. "how often in the past month did your spouse fail to spend enough time with you?"), and rejection or neglect (e.g. "how often in the past month did your spouse act unsympathetic or critical about your personal concerns?"). Both patient and caregiver were each asked to rate on a 5-point Likert scale ranging from 0 (never) to 4 (very often) how often in the previous month the other person provided these positive and negative exchanges.

Composite positive and negative social exchanges subscales were used in this study as they provide a broad assessment of positive and negative social exchanges with parallel content and comparable reliability (Newsom et al, 2005). The PANSE is suitable for chronic illness and late life research and has a good internal consistency of $\alpha = .94$ for the positive social exchanges and $\alpha = .84$ for negative social exchanges (Newsom et al, 2003; Newsom et al, 2005; Mavandadi, Sorkin, Rook, & Newsom, 2007; Mavandadi et al, 2014). Both subscales showed good internal consistency in the current study; positive social exchanges had Cronbach's alphas of .85 and .89 for caregivers and patients respectively, and .73 and .79 for the negative social exchanges scale for caregivers and patients respectively.

Depression

The 15-item Geriatric Depression Scale (GDS-15) assessed depressive symptoms in both patients and caregivers. Participants answered the first 4 questions of the scale (e.g. "Are you basically satisfied with your life?"). If the participant disagreed with any of these 4 statements then the remaining 11 statements were presented. There is a cutoff score of >5 that suggests clinically significant symptoms of depression. The GDS-15 is a useful discriminator between depressed and non-depressed PD patients (e.g. Meara, Mitchelmore, & Hobson, 1999; Mondolo et al, 2006; Weintraub, Xie, Karlawish, & Siderowf, 2006; Schrag et al, 2007; Pfeifer et al, 2013). The GDS-15 has good internal consistency with a Cronbach's alpha of .92 (Weintraub et al, 2006). In the current study the GDS-15 produced a Cronbach's alpha of .97 for both caregiver and patient groups.

Anxiety

The Hospital Anxiety and Depression Scale (HADS) is a 14-item scale that measures both anxiety and depression. In the current study, only the HADS-Anxiety (HADS-A) subscale was used. The 7 items for the HADS-A are rated on a four point scale ranging from

0 (not at all) to 3 (most of the time), resulting in a possible maximum scores of 21. A cutoff score of >8 indicates a clinical significant level of anxiety. Previous studies have indicated the validity of using the HADS to screen for anxiety symptoms in both people with Parkinson's disease and caregivers (Quelhas & Costa, 2009). The HADS-A subscale has shown good internal consistency in other studies (e.g. Rodriguez-Blasquez, Frades-Payo, Forjaz, Pedro-Cuesta & Martines-Martin, 2009; Watkins et al, 2013; Tew et al, 2013). The HADS-A showed acceptable internal consistency in the current study with Cronbach's alpha of .82 and .65 for caregivers and patients respectively.

2.5 Caregiver Specific Measures

Caregiver Burden

The primary measure of caregiver burden in the current study was the Zarit Burden Interview (ZBI) (Zarit, Reever, & Bach Peterson, 1980; Zarit, Orr, Zarit, 1985). The ZBI identifies the impact of patient disability on the caregiver/significant other in terms of health, finances, social life and interpersonal relations. Scores are unrelated to age, gender, living situation, locale, language, marital status or employment status (Schulz & Sherwood, 2008). Respondents make ratings to statements such as "Do you feel you should be doing more for your relative?" and "Do you feel strained when around your relative?". The degree to which caregivers agree with each item is rated along a 5-point Likert-type scale ranging from 0 (never) to 4 (nearly always). Higher scores indicate greater caregiver/significant other distress.

ZBI scores between 0-20 suggests no to mild burden; 21-40 suggests mild to moderate burden; 41-60 indicates moderate to severe burden and 61-88 suggests severe burden (Zarit, Reever, & Bach-Peterson, 1980). Schreiner, Morimoto, Arai and Zarit (2006) suggested that a cut-off score of 24-26 has significant predictive validity for identifying

caregivers at risk for negative psychological outcomes. The ZBI is widely used in caregiver research and has been used in PD, Alzheimer's and dementia research (Clyburn et al, 2000; Martinez-Martin et al, 2007; Leroi et al, 2012; Bekhet, 2013; Pfeifer et al, 2013; Mavandadi et al, 2014; Paradise et al, 2015). In the current study, the ZBI produced a Cronbach's alpha of .88.

Positive Aspects of Caregiving

The Positive Aspects of Caregiving Scale (PAC) (Tarlow et al, 2004) is a 9-item self-report measure that asks caregivers to rate their caregiving experience on a number of statements that include: Caregiving/providing help to _____ has; "Made me feel more useful" and "Made me feel important". Respondents rate their experience on a 5-point Likert scale ranging from 1 (disagree a lot) to 5 (agree a lot). The items are summed to give a total score for each participant. The PAC scale has been used in Alzheimer's disease and has shown good internal consistency (Cronbach's alpha of .89, Tarlow et al., 2004). In the current study this scale produced a Cronbach's alpha .94.

Hours Spent Caregiving

Caregivers were asked to approximate the hours they spent caring for the PD-MCI patient on a weekly basis. Caring activities ranged from simple tasks such as helping the patient with doing buttons on their shirts to showering the patient on a daily basis.

2.6 Statistical Analysis

Analyses were conducted using SPSS Version 23 and Amos Graphics 23. T tests examined differences between the patient-caregiver pairs. Correlations were used to examine associations between demographic, clinical and psychosocial variables for patients and caregivers, separately and between. Effect sizes (following Cohen, 1992) are also provided.

Structural equation modeling examined actor and partner effects using the Actor-Partner-Interdependence Model (APIM) (Kenny, Kashy, & Cook, 2006). Within the APIM

framework, actor effects refer to the relationship between a person's score on a predictor variable, such as positive social exchanges, and their *own* score on an outcome variable, such as relationship quality (paths A1 and A2 in Figure 1). Partner effects refer to the relationship between a person's score on a predictor variable and their *partner's* score on an outcome variable (paths P1 and P2 in Figure 1). In the APIM, non-independence of the data is addressed by estimating actor and partner effects simultaneously whilst controlling for shared variance in predictor and outcome variables (by estimating the correlation between the predictor variables and the error variances of the outcome variables). Following Kenny's recommendation (Kenny et al, 2006), unstandardized path coefficients are reported. To control for the influence of clinical characteristics of the patients, clinical variables correlating significantly with any of the outcome variables were included in the dyadic models as covariates. An example of the APIM model used in the current analysis is shown in Figure 1.

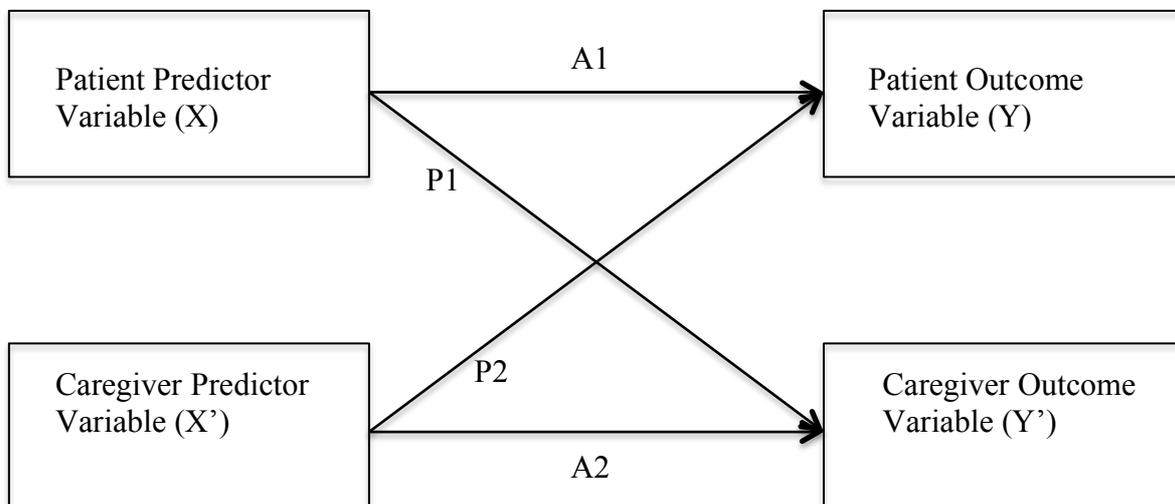


Figure 1. Model of the actor-partner interdependence model (APIM). from the work of Kenny and Cook, 1999.

X represents the predictor (positive exchanges, negative exchanges and mutuality) variable for the patient in the current study, and X' represents the predictor variable (positive exchanges, negative exchanges and mutuality) for the caregiver. Y and Y' represent the

outcome variables (relationship quality, anxiety and caregiver burden); that is X is presumed to cause Y and the two causal variables are allowed to be correlated. In this model, the horizontal effects are the actor effects, and the crossed effects are the partner effects.

3 RESULTS

3.1 Sample Characteristics and Descriptive Statistics

Demographic and clinical details for PD-MCI patients are shown in Table 2. The PD-MCI patients were mostly male and on average two years older than their caregiver ($t(29) = 4.35, p = < .01$). Both groups had around 13 years education and most identified themselves as New Zealand European, except one identified themselves as New Zealand Maori, one as Chinese, one as American, one as British, one as French and one as Greek. Only 4 out of 30 PD-MCI patients reported still working part or full time. Disease duration ranged from 1 to 16 years, with a mean of 8.3 years. Global neuropsychological performance for PD-MCI patients was expressed as an aggregate Z score for each patient obtained by averaging their standardized scores within four cognitive domains (executive function, attention, working memory and processing speed, visuospatial/visuoperceptual and learning and episodic memory) and taking the mean of these four scores (Table 2). The current patient sample performed similarly to previous studies of PD-MCI individuals conducted by Jones (2013) and Dalrymple-Alford and colleagues (2011) on these neuropsychological assessments. A summary of PD-MCI patient neuropsychological scores is shown in Table 1.

Caregivers were all spouses of the PD-MCI patients, and thus predominantly female. Like patients, most caregivers identified themselves as New Zealand European, except one person identified themselves as New Zealand Maori, another as Chinese and another as British. 11 of the 30 caregivers reported still working part or full time and one person identified themselves as being unemployed. Caregivers reported spending an average of 14.93 (Range = 0 - 80) hours caring for the PD-MCI patient on a weekly basis. The mean duration of the spousal relationship for the dyads was 41.3 years (Range = 5.5 - 62).

Table 2. Demographic Details for PD-MCI patients (N=30) and Caregivers (N=30)

	<i>PD-MCI Patient</i>	<i>Caregiver</i>
Age	71.9 (8.04)	67.9 (8.7)
Sex, M:F	24:6	6:24
Ethnicity:NZer:Other	24:6	27:3
Retired:Other	26:4	19:11
Education (Years)	12.9 (2.8)	13.6 (2.7)
Disease Duration	8.3 (3.9)	-
Hoehn & Yahr	2.4 (0.6)	-
UPDRS-Pt 1	11.8 (4.8)	-
UPDRS-Pt 2	14.7 (6.0)	-
UPDRS-Pt 3	37.3 (12.7)	-
MoCA	23.3 (3.2)	-
WTAR (IQ)	109.4 (9.2)	-
Hours Caring	-	14.9 (25.4)

Note: Mean (*SD*) or number of cases are presented

MoCA Montreal Cognitive Assessment; UPDRS-Pt 1-3 Universal Parkinson's Disease Rating Scale; WTAR (IQ) Wechsler Test of Adult Reading.

Means and standard deviations for key psychiatric and psychosocial variables in the study are shown in Table 3. Paired sample t-tests were conducted to investigate differences between patients and caregivers on relationship satisfaction, positive and negative social interactions, mutuality and well-being (anxiety and depression). The only significant difference between these measures was that patients reported receiving more negative interactions from their caregiver than the caregiver reported receiving from their patient. The low values in Table 3 indicate that these negative interactions were relatively infrequent. Both patients and caregivers reported high relationship satisfaction, positive social exchanges and mutuality.

In terms of depression and anxiety, only four patients scored over the cut-off for the depression (<5 for the GDS), and 2 for anxiety (<8 for HADS-A). Similarly, only one caregiver scored above the cut-off for depression and two for anxiety. This is comparable to other studies examining PD-MCI patients and their caregivers (Jones, 2013). In the current study, 23% of the caregivers showed significant caregiver burden scores (i.e., scoring at or

above the cutoff of 24 proposed by Schreiner et al, 2006). This percentage is lower than found by Jones (2013).

Table 3. Paired-samples t test analysis of variables of dyadic relationship functioning and well-being in PD-MCI patients and caregivers

	PD-MCIs		Caregivers		<i>t</i>	<i>p</i>
	<i>M</i>	(<i>SD</i>)	<i>M</i>	(<i>SD</i>)		
Relationship satisfaction	4.49	(0.53)	4.44	(0.49)	0.42	.675
GDS	1.13	(2.18)	0.53	(1.46)	-1.15	.258
HADS-A	3.33	(2.60)	2.40	(3.25)	1.17	.251
P-SE	3.14	(0.64)	2.97	(0.68)	-1.20	.238
N-SE	1.14	(0.55)	0.67	(0.46)	4.00	.000
Mutuality	3.40	(0.57)	3.38	(0.45)	0.25	.801
ZBI			14.97	(10.25)		
PAC			30.8	(8.97)		

GDS Geriatric Depression Scale; HADS-A Hospital Anxiety and Depression Scale-Anxiety Subscale; N-SE Negative Social Exchanges Subscale; P-SE Positive Social Exchanges Subscale; PAC Positive Aspects of Caregiving; ZBI Zarit Burden Interview.

3.2 Patient-Caregiver Correlations

Table 4 presents the correlations between the clinical and general cognitive characteristics of the patient and the key psychiatric and psychosocial variables in the study. Only five correlations were significant: Patients with higher UPDRS-Pt 2 scores (motor aspects of daily living) were more anxious, and had caregivers who reported receiving fewer positive interactions from the patient. Caregivers of patients with higher UPDRS-Pt 3 scores (motor impairments) were less satisfied with their relationship. Caregivers of patients with higher pre-morbid IQ scores (WTAR) reported higher mutuality and were less likely to report positive aspects of caregiving. These correlations were all of a moderate ($r > .30$) to large ($r > .50$) magnitude according to Cohen (1992). Two additional two moderate size correlations just failed to reach significance: patients with a worse global cognitive score had caregivers who were less satisfied with their relationship and patients with higher UPDRS-Pt 1 scores reported receiving fewer positive interactions.

Table 4. Correlations between measures of dyadic relationship functioning, well-being and clinical and general cognitive characteristics of the PD patients

	Global Z Score	Hoehn and Yahr Score	UPDRS Pt 1 (Non- Motor ADL)	UPDRS Pt2 (Motor ADL)	UPDRS Pt 3 (Motor Pt 2)	MoCA	WTAR (IQ)
Patient Variables							
Rel Sat	-.04	.08	-.26	.02	.09	.02	.05
GDS	.06	-.17	.08	.04	-.07	-.14	.08
HADS-A	-.07	.26	.28	.36*	.18	.05	-.08
P-SE	-.03	.02	-.31+	-.02	.13	-.04	.22
N-SE	-.11	-.07	.21	.13	.01	-.14	-.14
Mutuality	.10	.08	-.27	-.14	.06	.08	.23
Caregiver Variables							
Rel Sat	-.36+	.28	-.04	.04	.58**	-.18	.15
GDS	.11	.01	.03	-.20	-.01	.16	.20
HADS-A	-.01	-.06	.03	-.22	-.22	.15	.23
P-SE	-.08	-.06	-.23	-.38*	-.01	.17	.23
N-SE	.12	.05	.15	.13	-.25	.14	-.27
Mutuality	.03	.09	.01	-.22	.18	.12	.43*
ZBI	.21	.05	.12	.17	-.18	.10	-.08
PAC	-.08	-.09	-.20	-.09	-.20	-.02	-.50**

Pearson correlations; + $p < .10$, * $p < .05$, ** $p < .01$, two tailed.

GDS Geriatric Depression Scale; HADS-A Hospital Anxiety and Depression Scale-Anxiety Subscale; MoCA Montreal Cognitive Assessment; N-SE Negative Social Exchanges Subscale; P-SE Positive Social Exchanges Subscale; PAC Positive Aspects of Caregiving; Rel Sat Relationship Satisfaction; UPDRS-Pt1-3 Universal Parkinson's Disease Rating Scale; WTAR (IQ) Weschler Test of Adult Reading; ZBI Zarit Burden Interview.

Table 5 shows the correlations for patients between the social interaction variables, relationship satisfaction and well-being. Correlations revealed that patients' who reported more positive and fewer negative interactions, and who reported higher levels of mutuality, were more satisfied with their relationship; these were all large correlations ($r > .50$) (Cohen, 1992). Moderate sized correlations were found between anxiety and positive social exchanges and mutuality respectively (although the correlation between mutuality and anxiety did not reach significance, indicating that patients who reported more positive interactions and mutuality were less anxious. There were no significant correlations between any of the variables and patient depression (and all were of small magnitude). Moderate to strong

correlations were found between the social interaction variables: patients who reported more positive exchanges, also reported higher mutuality and fewer negative exchanges, and patients who reported few negative exchanges also reported higher mutuality.

Table 5. Correlations between measures of dyadic relationship functioning and well-being for PD-MCI patients

	Rel Sat	GDS	HADS-A	P-SE	N-SE
Rel Sat					
GDS	-.02				
HADS-A	-.17	.02			
P-SE	.68**	-.13	-.36*		
N-SE	-.72**	.11	.24	-.45*	
Mutuality	.81**	-.18	-.31+	.86**	-.64**

Pearson correlations; + $p < .10$, * $p < .05$, ** $p < .01$, two tailed.

GDS Geriatric Depression Scale; HADS-A Hospital Anxiety and Depression Scale-Anxiety Subscale; N-SE Negative Social Exchanges Subscale; P-SE Positive Social Exchanges Subscale; Rel Sat Relationship Satisfaction.

Table 6 shows the correlations for caregivers between the social interaction variables, relationship satisfaction and well-being. Like patients, caregivers who reported more positive social interactions, fewer negative social interactions and higher mutuality, were more satisfied with their relationship and these were all large correlations ($r > .50$). In addition, a strong correlation between mutuality and burden was also found; caregivers who reported higher mutuality reported lower caregiver burden. A large correlation between depression and anxiety was found, suggesting comorbidity of depressive and anxious symptomatology in caregivers. Positive social interactions were moderately ($r > .30$) correlated with negative social interactions and strongly correlated with mutuality, with caregivers who reported greater positive social interactions reporting fewer negative social interactions and higher mutuality. A positive large correlation was found for positive social interactions and the hours spent caring for the patient, but negative social interactions was not associated with time spent caregiving. A large negative correlation between relationship satisfaction and ZBI was also found; caregivers who reported being more satisfied with their relationship reported fewer feelings of caregiver burden.

Table 6. Correlations between measures of dyadic relationship function and well-being in caregivers

	Rel Sat	GDS	HADS-A	P-SE	N-SE	Mutuality	ZBI	PAC
Rel Sat								
GDS	-.20							
HADS-A	.14	.51**						
P-SE	.54**	-.01	.05					
N-SE	-.65**	-.30+	-.23	-.37*				
Mutuality	.58**	-.07	.04	.78**	-.56**			
ZBI	-.65**	.06	-.10	-.26	-.35+	.58**		
PAC	.01	-.25	-.32+	-.07	.25	.10	-.07	
Hours Caring	-.16	.05	-.15	.53**	-.01	.16	.08	.13

Pearson correlations; + $p < .10$, * $p < .05$, ** $p < .01$, two tailed.

GDS Geriatric Depression Scale; HADS-A Hospital Anxiety and Depression Scale-Anxiety Subscale; N-SE Negative Social Exchanges Subscale; P-SE Positive Social Exchanges Subscale; PAC Positive Aspects of Caregiving; Rel Sat Relationship Satisfaction; ZBI Zarit Burden Interview.

3.3 Patient-Caregiver Associations

Table 7 presents the correlations between measures of dyadic relationship functioning and well-being in PD-MCI patients and their caregivers. Moderate correlations were found between patient and caregiver reports of relationship satisfaction and mutuality (correlations on the diagonal) indicating there was substantial agreement between patients and caregivers regarding the quality of their relationship and the level of mutuality. Correlations between patient and caregiver reports of positive and negative interactions were not significant (and all of small magnitude). Instead, strong negative correlations were found between one spouse's report of positive interactions and the other spouse's report of negative interactions. Thus, when one spouse reported receiving more positive interactions, fewer negative interactions were reported. Correlations between relationship satisfaction and positive and negative social interactions are in the same direction for both patients and caregivers and are all of moderate magnitude, although are not significant at $p < .05$.

Moderate effects were found between patients and caregivers on measures of psychiatric well-being (depression and anxiety) and positive and negative social interactions. Patients reporting higher levels of anxiety had caregivers who were reporting greater negative interactions in the relationship. There were no significant correlations between patient

depression and any caregiver measures of psychiatric and psychosocial well-being. Patient relationship satisfaction was moderately correlated with caregiver mutuality and positive social interactions, suggesting that when caregivers perceived greater mutuality and positive interactions in the relationship, the patient rated their relationship satisfaction as higher.

Patients reported fewer negative social interactions when caregiver mutuality was high and when there were greater positive social interactions. Patient mutuality revealed strong correlations with caregiver positive and negative social interactions; when caregivers perceived greater positive social interactions, patients reported greater levels of mutuality. Similarly, less negative interactions reported from the caregiver also contributed to higher levels of patient mutuality. There were no significant correlations found between caregiver depression, anxiety, caregiver burden, positive aspects of caregiving or hours spent caregiving and patient variables in the current study.

Table 7. Correlations between measures of dyadic relationship functioning and well-being in PD-MCI patients and caregivers

	Patient Variables					
	Rel Sat	GDS	HADS-A	P-SE	N-SE	Mutuality
Caregiver Variables						
Rel Sat CG	.40*	.04	-.13	.34	-.36	.35+
GDS	-.01	-.20	-.21	.09	-.17	.10
HADS-A	.12	-.07	-.10	.17	-.14	.19
P SE	.47**	-.07	-.26	.23	-.50**	.38*
N SE	-.30+	.01	.50**	-.50**	.20	-.51**
Mutuality	.45*	-.06	-.21	.32+	-.53**	.55**
ZBI	-.17	.06	.23	-.12	.15	-.13
PAC	.27	.15	.03	-.13	.08	.01
Hours Caring	.05	-.10	.11	.01	.06	.08

Pearson correlations; + $p < .10$, * $p < .05$, ** $p < .01$, two tailed.

GDS Geriatric Depression Scale; HADS-A Hospital Anxiety and Depression Scale-Anxiety Subscale; N-SE Negative Social Exchanges Subscale; P-SE Positive Social Exchanges Subscale; PAC Positive Aspects of Caregiving; Rel Sat Relationship Satisfaction; ZBI Zarit Burden Interview.

3.4 Dyadic Analyses

Actor-partner interdependence models (APIM) were tested to investigate dyadic interactions. As discussed earlier, the UPDRS-Pt 2 correlated significantly with patient anxiety, and the UPDRS-Pt 3 correlated significantly with caregiver relationship satisfaction (see Table 4). To control for the influence of these variables on the relevant dependent variables, I added a path from the UPDRS-Pt 2 to patient anxiety in the models, with anxiety as the dependent variable, and a path from the UPDRS-Pt 3 to caregiver relationship satisfaction in the models, with relationship satisfaction as the dependent variable. Positive aspects of caregiving (PAC) was not used as a dependent variable in APIM models as the correlations between the social interaction variables for PD-MCI patients and caregivers revealed no significant relationships with this variable. This was also the case with the GDS; correlations between social interaction variables for patients and caregivers revealed no significant relationships with depression.

Table 8 shows the effects of positive social exchanges on the dependent variables, relationship satisfaction, anxiety and caregiver burden for both patients and caregivers. Where both actor and partner effects are found, the findings are also illustrated in a figure. Significant actor effects (the influence of a person's own predictor variable on their own outcome variable) were found for positive social interactions on relationship satisfaction for both patient and caregiver (see Figure 2); patients and caregivers receiving more positive social interactions reported greater perception of relationship satisfaction. A significant partner effect (the influence of a person's variable on their partner's outcome variable) was found for caregiver positive social exchanges on patient relationship satisfaction (see also Figure 2); that is, caregivers who reported receiving many positive interactions from their ill spouse had spouses (patients) who reported higher relationship satisfaction. This was not found for the reverse however, thus, there was no partner effect found for patient positive

social exchanges on caregivers' perception of relationship quality. A total of 57% and 65%, respectively, of the variance in relationship satisfaction for patients and caregivers, was explained by the variables included in this model.

A significant actor effect was found for positive social exchanges on anxiety for patients only (see Table 8); patients who reported receiving greater positive social interactions also reported being less anxious. No other actor or partner effects were found for positive social exchanges on anxiety. A total of 25% and 3% of the variance in anxiety for patients and caregivers, respectively, was explained by the variables included in the model.

There were no significant actor or partner effects of positive social exchanges on caregiver burden, although the actor effect approached significance. A total of 12% of the variance in this model was explained by positive social exchanges and caregiver burden in this model.

Table 8. APIM analysis of positive social exchanges and relationship satisfaction, anxiety and caregiver burden

	b	SE	p	R ² PD	R ² CG
Relationship Satisfaction ¹				.57	.65
P-SE (PD) → Rel Sat (PD)	0.50	0.10	.000		
P-SE (CG) → Rel Sat (CG)	0.37	0.11	.002		
P-SE (CG) → Rel Sat (PD)	0.25	0.10	.009		
P-SE (PD) → Rel Sat (CG)	0.11	0.09	.210		
HADS-Anxiety ²				.25	.03
P-SE (PD) → HADS-A (PD)	-1.40	0.67	.035		
P-SE (CG) → HADS-A (CG)	0.07	0.90	.940		
P-SE (CG) → HADS-A (PD)	-0.18	0.63	.780		
P-SE (PD) → HADS-A (CG)	0.82	0.95	.390		
ZBI					.12
P-SE (PD) → ZBI (CG)	-0.71	2.90	.803		
P-SE (CG) → ZBI (CG)	-5.04	2.70	.061		

Note: ¹ controlling for the relationship between UPDRS-Pt 3 and caregiver relationship satisfaction; ² controlling for the relationship between UPDRS-Pt 2 and patient anxiety.

PD Parkinson's disease Patient; CG Caregiver; HADS-A Hospital Anxiety and Depression Scale Anxiety Subscale; P-SE Positive Social Exchanges; Rel Sat Relationship Satisfaction; ZBI Zarit Burden Interview.

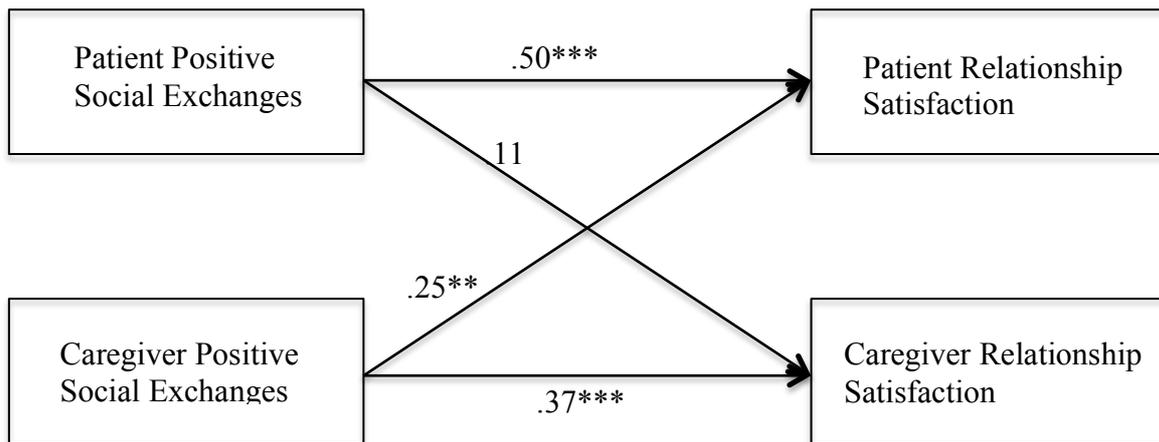


Figure 2. APIM of Positive Social Exchanges and Relationship Satisfaction. Pathways are significant at the * $p < .001$, ** $p < .01$. Unstandardized regression weights controlling for UPDRS-Pt 3.**

Table 9 shows the dyadic effects of negative social exchanges on relationship satisfaction, anxiety and caregiver burden. Like positive social exchanges, there were significant actor effects of negative social exchanges on relationship satisfaction for patient and caregiver in this model. Patient’s and caregiver’s own ratings of negative social exchanges negatively influenced their own relationship satisfaction. A significant partner effect of negative social exchanges from the patient (Figure 3) had an effect on the relationship satisfaction of the caregiver; more negative interactions from the patient was related to lower caregiver relationship satisfaction (see also Figure 3).

A significant actor effect of patients’ perceived positive social exchanges on their own anxiety was also found; patients who reported receiving more positive interactions were less anxious. A significant partner effect of negative social exchanges from the caregiver on patient anxiety was found in this model; patients who reported receiving greater negative social interactions from their caregiver reported being more anxious (see also Figure 4). Furthermore, a significant actor effect of caregiver negative social exchanges and caregiver burden was also found in this model; caregivers who reported greater negative social interactions experienced greater levels of burden.

Table 9. APIM analysis of negative social exchanges and relationship satisfaction, anxiety and caregiver burden

	b	SE	p	R ² PD	R ² CG
Relationship Satisfaction ¹				.55	.63
N-SE (PD) → Rel Sat (PD)	-0.67	0.12	.000		
N-SE (CG) → Rel Sat (CG)	-0.50	0.11	.000		
N-SE (CG) → Rel Sat (PD)	-0.19	0.14	.181		
N-SE (PD) → Rel Sat (CG)	-0.24	0.10	.013		
HADS-Anxiety ²				.32	.06
N-SE (PD) → HADS-A (PD)	0.56	0.73	.460		
N-SE (CG) → HADS-A (CG)	-1.50	1.29	.250		
N-SE (CG) → HADS-A (PD)	2.39	0.86	.006		
N-SE (PD) → HADS-A (PD)	-0.57	1.09	.610		
ZBI					.34
N-SE (PD) → ZBI (CG)	0.70	2.30	.812		
N-SE (CG) → ZBI (CG)	12.70	3.41	.000		

Note: ¹ controlling for the relationship between UPDRS-Pt 3 and caregiver relationship satisfaction; ² controlling for the relationship between UPDRS-Pt 2 and patient anxiety.

PD Parkinson's disease Patient; CG Caregiver; HADS-A Hospital Anxiety and Depression Scale Anxiety Subscale; N-SE Negative Social Exchanges; Rel Sat Relationship Satisfaction; ZBI Zarit Burden Interview.

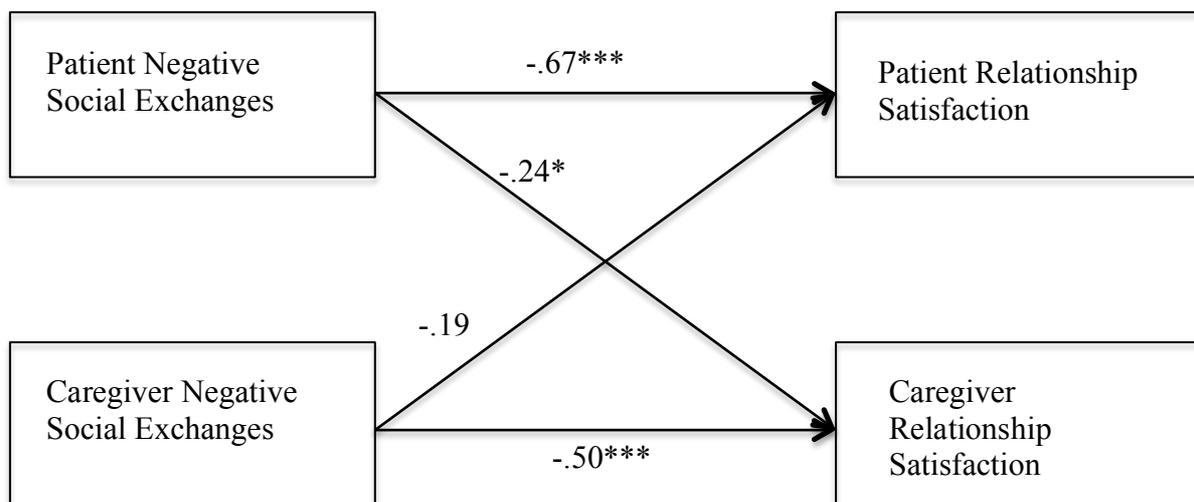


Figure 3. APIM of Negative Social Exchanges and Relationship Satisfaction. Pathways are significant at the *p<.001, ** p <.01 and * p <.05 level. Unstandardized regression weights controlling for UPDRS-Pt 3.**

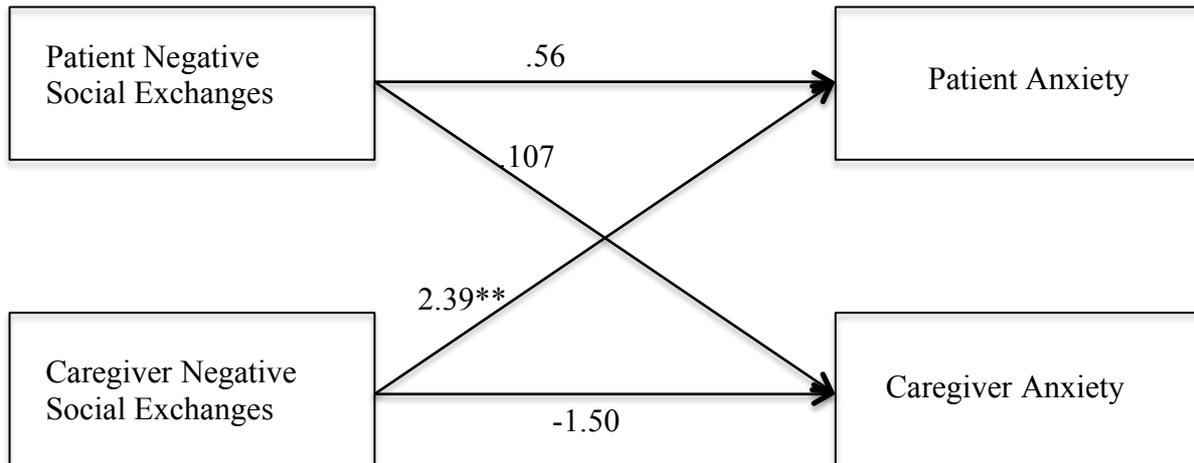


Figure 4. APIM of Negative Social Exchanges and Anxiety. Pathways are significant at ** $p < .01$ level. Unstandardized regression weights controlling for UPDRS-Pt 2.

Table 10 shows the dyadic effects of mutuality on relationship satisfaction, anxiety and caregiver burden. Significant actor effects of mutuality and relationship satisfaction for both patient and caregiver were found; patients and caregivers who reported higher mutuality were more satisfied with their relationships. No significant partner effects were found in the mutuality model. The mutuality and anxiety, and mutuality and caregiver burden models revealed no significant actor or partner effects, suggesting that mutuality had no influence on patient or caregiver anxiety, or caregiver burden.

Table 10. APIM analysis of mutuality and relationship satisfaction, anxiety and caregiver burden

	b	SE	p	R ² PD	R ² CG
Relationship Satisfaction ¹				.66	.34
Mutuality (PD) → Rel Sat (PD)	0.76	0.12	.000		
Mutuality (CG) → Rel Sat (CG)	0.49	0.16	.002		
Mutuality (CG) → Rel Sat (PD)	0.01	0.15	.990		
Mutuality (PD) → Rel Sat (CG)	0.07	0.12	.594		
HADS-Anxiety ²				.18	.04
Mutuality (PD) → HADS-A (PD)	-1.22	0.97	.181		
Mutuality (CG) → HADS-A (CG)	-0.72	1.58	.650		
Mutuality (CG) → HADS-A (PD)	0.05	1.16	.970		
Mutuality (PD) → HADS-A (CG)	1.42	1.25	.254		
ZBI					
Mutuality (PD) → ZBI (CG)	0.36	3.90	.930		.07
Mutuality (CG) → ZBI (CG)	-6.28	4.90	.200		

Note: ¹ controlling for the relationship between UPDRS-Pt 3 and caregiver relationship satisfaction; ² controlling for the relationship between UPDRS-Pt 2 and patient anxiety.

PD Parkinson's Disease Patient; CG Caregiver; HADS-A Hospital Anxiety and Depression Scale Anxiety Subscale; Rel Sat Relationship Satisfaction; ZBI Zarit Burden Interview.

4 DISCUSSION

The current study sought to investigate dyadic interactions in PD-MCI patients and their primary caregivers, in terms of supportive and unsupportive dyadic interactions and mutuality on relationship satisfaction, psychological well-being and caregiver burden. Prior research investigating PD patients and their caregivers has generally focused on disease-related variables and individual outcomes. Furthermore, there is previous research that provides support for social interactions influencing psychological well-being and relationship quality in PD patients and their caregivers. There are however, very few studies examining dyadic interactions in PD, and this is the first to investigate dyadic interactions in PD-MCI patients and their caregivers. This research aimed to examine the relationship between supportive and unsupportive dyadic interactions, and the psychological functioning of both patients and caregivers.

4.1 Initial Findings

Initial bivariate analyses revealed that both patients and caregivers in the current study reported high relationship quality and these ratings revealed a moderate correlation. Similarly, both patients and caregivers reported high mutuality in the relationship and this was further supported with a strong correlation between patient and caregiver ratings of relationship mutuality (the quality of interactions or reciprocity of sentiment in a relationship), which is comparable to the findings of Tanji et al (2008) and Shim et al (2011). High levels of perceived positive social interactions were also reported by both individuals, and far fewer negative social interactions were experienced as per the low means found in the current sample and this finding is consistent with previous research showing that negative psychological outcomes could be offset by positive social interactions in the relationship (i.e., when both partners receive and provide support) (e.g., Kleiboer et al, 2007). There was

however, a significant difference between patients and caregivers in their reports of negative social interactions, with patients reporting greater negative interactions compared to caregivers; possibly due to patients assuming that the negative interactions they received were because of PD and associated impairments. Anxiety and depression were not clinically significant in this sample, and this was supported by the low means found for both patients and caregivers. This was also due to only a few patients and caregivers scoring above the cut-off for clinically significant depression and anxiety in the current study. Additionally, low levels of depression and anxiety in the current study could also be associated to the use of medications in PD patients, with research suggesting that, for example, Levodopa, can mitigate feelings of depression due to reuptake of dopamine in the brain, as it is thought that depression occurs in PD when there are periods of dopamine deficiency as the disease progresses (c.f. Connolly & Fox, 2011). This in turn could influence caregiver ratings of anxiety and depression as it has been found that caregiver burden and associated psychological distress is more common when caring for a PD patient with mood related symptoms, and this was not the case in the current study (Carter et al, 2008; Connolly & Fox, 2011). Caregivers also had low means in terms of caregiver burden, with only few caregivers scoring above the recommended cut-off for clinically significant levels of burden, and moderate levels of positive aspects of caregiving. The low means found for caregiver burden in the current study could also reflect the low mean of hours spent caring for the PD patient by the caregiver. Although moderate levels of positive aspects of caregiving were found, caregivers frequently expressed concern with the nature of the questions, and this may have influenced the caregiver responses:

“Caregiving hasn’t made me feel good about myself; I do it because he needs me. It’s not about me”

Levels of depression and anxiety for patients and caregivers in the current study were similar to that found in previous research with PD-MCI patients conducted by Jones (2013). Furthermore, the clinical characteristics and assessment scores of the PD-MCI patients were similar to those found by Leroi and colleagues (2012), Jones (2013) and Szeto and colleagues (2016). Positive aspects of caregiving were higher, and caregiver burden scores were lower to those found in the Jones 2013 study.

4.2 Cognitive and Clinical Status

It was hypothesized that cognition/clinical status would be associated with social interactions and psychological functioning of patients and caregivers. On the whole, there were not that many significant associations between clinical and cognitive assessment variables and the key relationship and psychological functioning outcomes in the current study, with the exception of a few moderate to strong correlations. Disease severity and cognition assessed by the MoCA was not significantly associated with any social interaction or psychological functioning variables. This is a surprising finding as quite often these clinical variables for patients are associated with psychological functioning for patients and caregivers (i.e., anxiety, depression, caregiver burden) (Martinez-Martin et al, 2007; Dissanakaya et al, 2011; Zhong, Peppard, Velaloulis & Evans, 2016).

Clinical variables that did reveal significant findings were the global cognitive z score, UPDRS and premorbid intellectual functioning. A moderately strong relationship was found between caregiver relationship quality and the average global cognitive score of the patients. This is in line with previous research showing that worsening cognition is related to poorer relationship quality for caregivers (Garand et al, 2007; Roberto, McCann & Blieszner, 2011). Moreover, a moderately strong, negative correlation was found between part one of the UPDRS (non-motor aspects of daily living) and positive social interactions reported by patients. Patients experiencing higher levels of impairment in non-motor aspects of daily

living perceived fewer positive interactions from their caregiver. A possible explanation for this is that patients may have perceived the positive interactions from their caregivers as assistance on tasks they could no longer do independently, influencing their perceptions of the interaction, and this could further be associated with patients focusing on social interactions from a disease-focused perspective.

Furthermore, part two of the UPDRS (motor aspects of daily living) was moderately correlated with patient anxiety. Prior research supports this, as it has been suggested that lower levels of psychological functioning are present when patients report greater levels of motor fluctuation (Tanji et al, 2008). Part two and three of the UPDRS were related to caregivers' perceived positive social interactions and relationship quality, respectively, suggesting that caregivers reported receiving less positive social interactions from their patients and being less satisfied with the relationship when there was a greater influence of motor complications in everyday life. The UPDRS asks questions surrounding motor complications such as eating and dressing, as well as more disease focused questions. These associations are an interesting finding, and are supported with prior research that has found changes and fluctuations in motor abilities, thus disability, influence role changes and decrease positive relationship interactions for caregivers of PD patients (Tanji et al, 2008; Ricciradi et al, 2015).

Finally, a strong correlation was found between premorbid intellectual functioning and mutuality and positive aspects of caregiving for the caregiver. Caregivers of patients with higher levels of premorbid intellectual functioning reported higher mutuality in their relationship, and this is consistent with previous research that has found that higher levels of mutuality in the relationship are found when there is less impairment (Archbold et al, 1990; Tanji et al, 2008; Shim, Landerman & Davis, 2011). However, the opposite was found for positive aspects of caregiving; with caregivers reporting fewer positive aspects of caregiving

when patients had higher premorbid intellectual functioning. A possible explanation for this is that with MCI, intellectual functioning decreases as impairment in cognitive ability increases. This may cause caregivers to feel as if they are losing their loved one and how they used to interact with each other, and this could influence a negative opinion of the caregiving process.

4.3 Dyadic Interactions

The main focus of the current study was to investigate the dyadic processes between PD-MCI patients and their caregivers in terms of social interactions, psychological and relationship functioning. Dyadic interactions in PD patients and their caregivers have previously focused on only caregiver outcomes (Szeto et al, 2016), mutuality (Tanji et al, 2008; Lyons et al, 2009; Shim et al, 2011), relationship quality (Ricciardi et al, 2015) or positive aspects of caregiving in terms of benefit finding (Mavandadi et al, 2014). However, there has not been a study that has focused on social interactions, psychological and relationship functioning between PD patients with MCI and their caregivers. APIM models were tested to investigate social interaction variables on relationship quality, anxiety and burden. Depression was not included in APIM analyses due to null significance with the social interaction variables in the current sample; this may have been due to the low levels of depression in the patients and caregivers in the current study. Significant correlations between patient clinical variables were found for some of the key variables in the current study (i.e., relationship quality and anxiety), and so these were controlled for as covariates in the model analyses. After adjusting for significant clinical variables in the current study, the dyadic interactions remained significant.

Actor effects.

It was hypothesized that individuals experiencing more positive social interactions would report greater relationship quality and better psychological functioning compared to

those experiencing higher levels of negative social interactions. Supporting this hypothesis, significant actor effects were found for the influence of positive social interactions on relationship quality for both patients and caregivers. Thus, on average, individuals who experienced higher levels of positive social interactions with their partner were more satisfied with their relationship. This finding is in line with previous research investigating positive social interactions in relationships (Lakey et al, 2002; Melrose, Brown & Wood, 2015) and in PD dyads (Shim, Landerman & Davis, 2011; Mavandadi et al, 2014; Ricciardi et al, 2015). Furthermore, a significant actor effect was found for patients perceiving higher positive interactions on their levels of anxiety which shows that patients who reported receiving greater positive social interactions were less anxious. It is important to note however, that very few patients in the sample had clinically significant levels of anxiety and the means indicated relatively low levels of anxiety within the sample.

A significant actor effect was not found for positive interactions on caregiver burden in this sample; however, the path was approaching significance. Very few caregivers in the current study expressed being burdened per the cut-off, and the low mean indicates that those experiencing burden were only experiencing mild levels of burden. Furthermore, correlations revealed that there was a moderate correlation between positive interactions and burden scores for caregivers, suggesting that those caregivers who experienced more positive interactions were less burdened. This is an important finding, as it shows that positive interactions with the patient-spouse are important for the caregiver. By maintaining positive interactions with a partner that has PD, caregivers are able to feel less burdened and adjust to role changes within the relationship, as they may feel that the patient can still maintain reciprocity of these interactions. This is in line with prior research that has shown that perceived social support is an important predictor of caregiver burden (Pagninia et al, 2010; Bekhet, 2012)

It was also hypothesised that individuals experiencing more negative social interactions in their relationship would report being less satisfied with their relationship and experience greater levels of psychological distress. Supporting this hypothesis, significant actor effects were found for both patients and caregiver, that is, when patients and caregivers reported receiving greater negative social interactions, they were less satisfied with the relationship. Prior research also shows support for this finding, as negative interactions have been shown to influence how satisfied patients and caregivers are with their relationship (Simpson et al, 2006; Savla et al, 2011; Mavandadi et al, 2014)

No significant actor effects were found for the influence of negative social interactions on individual's anxiety, which is surprising as negative social interactions have previously been found to influence psychological distress in both patients and caregivers in PD (Ricciardi et al, 2015). A possible explanation for this is that the low levels of negative social interactions experienced in this study, as well as the current sample not exhibiting clinically significant levels of anxiety, as per the low means, suggest that the positive interactions and high relationship quality and mutuality are having more of an influence on patient and caregiver functioning.

There was however, a significant actor effect found for caregiver burden, suggesting that caregivers reported being more burdened when they reported experiencing more negative social interactions. This again is consistent with previous findings examining negative interactions and caregiver burden (Rapp et al, 1998; Pagninia et al, 2010).

Mutuality, another positive indicator of relationship functioning, also produced significant actor effects for both patients and caregivers on reports of relationship quality. Patients and caregivers reporting higher levels of mutuality in the relationship were more satisfied with their relationship. This is supported with previous research, as higher levels of mutuality in relationships have been associated with lower levels of burden and psychological

distress in PD patients and their caregivers (Tanji et al, 2008; Shim, Landerman & Davis, 2011). With both patients and caregivers reporting high levels of mutuality in the current study, it is not surprising that this had a strong influence on relationship quality. With prior research supporting that higher levels of mutuality in relationships is a protective factor of negative outcomes for both patients and caregivers, findings from the current study indicate that although patients have MCI in addition to PD, the dyads appear to be coping and adjusting to progressive changes of the disease.

No significant actor effects were found for the influence of mutuality on psychological functioning or caregiver burden in the current sample. A possible explanation for this is that both patients and caregivers were high in mutuality, and clinically significant levels of anxiety and caregiver burden were not found. Correlations also revealed no significant relationships between mutuality and anxiety for both patients and caregivers, or caregiver burden, so it was unlikely to have an influence in additional analyses.

Partner effects.

It was hypothesized that positive social interactions from one partner would influence the relationship quality reported by the other. Supporting this hypothesis, a significant effect of positive interactions perceived by the caregiver on the relationship quality reported by the patient was found. Thus, patients with caregivers reporting experiencing more positive social interactions were more satisfied with their relationships. This finding is in line with prior research demonstrating that experiencing more positive interactions in a relationship results in greater perceived relationship quality for both partners. The study conducted by Mavandadi and colleagues (2014) is the only other study to investigate partner effects using the APIM in PD patients and their spouses. Mavandadi and colleagues found that positive interactions associated with benefit finding (personal growth in the face of a stressor) from the patient influenced greater marital quality as reported by their spouse. The findings from

the current study and the work of Mavandadi and colleagues (2014), highlight the importance of reciprocity of interactions in the spousal relationship, thus, it is not just about what you receive in terms of positive interactions, but also what your partner reports receiving that contributes to your perceived relationship quality (cf. Kleiboer et al., 2006). Moreover, this may be more important for patients as they may not be able to contribute the same amount of support as their partner due to having PD, potentially influenced by the associated motor and cognitive complications that are now present within their relationship.

It was also hypothesized that negative social interactions would produce partner effects in terms of lower relationship quality and lower psychological functioning. Supporting this claim, a significant partner effect was found between negative social interactions reported by the patient and relationship quality reported by the caregiver. Thus, patients reporting experiencing more negative interactions had caregivers who were less satisfied with their relationship. Furthermore, patients reported receiving significantly more negative interactions than caregivers, and this could have influenced patients to withdraw from their role in the relationship and thus influence caregivers' ratings of relationship quality. Possible reasons for this relationship could be associated with the fact that often patients become so focused on disease variables (Quinn, Clare & Woods, 2009; Ricciardi et al, 2015), that their contribution to the relationship progresses from being that of a spouse to being a patient. Frustrations surrounding cognitive and motor problems, as suggested by relationships with the global cognitive and UPDRS scores, may further influence negative interactions and reduce relationship quality, as activities and behaviours that were once possible, are no longer achievable for these individuals.

There were no significant partner effects found for positive interactions perceived by the patient on caregiver anxiety or relationship quality. A possible explanation for this is that, caregivers reported high relationship quality and mutuality in the current study and may not

feel as if the positive interactions patients perceive are any different to how they were before their spouse was diagnosed with PD; furthermore, positive social interactions have been shown to reduce psychological distress, as per prior research (Feeney & Collins, 2003; Mavandadi et al, 2007; Newsom et al, 2005; Rook, 2015). Furthermore, there were no significant partner effects found for the influence of positive social interactions on levels of burden experienced by the caregiver. A potential explanation for this is that caregivers reporting higher levels of relationship quality appeared to report significantly lower levels of burden. This is an interesting finding and one that has not previously been reported, to our knowledge, in dyadic studies in PD or general caregiving populations. A potential explanation for this may be due in part to higher positive dyadic interactions combined with high levels of mutuality influencing dyadic coping and adjustment in the caregivers in this study.

A significant partner effect was found for negative social exchanges reported by the caregiver on patient anxiety. Thus, when caregivers reported receiving more negative interactions, the patient reported higher levels of anxiety. Caregivers reporting more negative interactions from their partner would more than likely engage in negatively interacting with the patient in response. This is supported by the differences found between patients and caregivers in terms of perceived negative interactions in the relationship. Another possible influence is that patient UPDRS-Pt 2 scores were significantly correlated with both patient anxiety and caregiver reports of positive social exchanges. One potential explanation for this is that motor fluctuations, suggested to influence psychological and relationship functioning, influenced caregivers' perceptions of positive social support, which were rated as lower when patient UPDRS-Pt 2 scores were higher. It is likely that patients also experiencing higher levels of motor complications would be more anxious, consistent with previous research (Rapp et al, 1998) which may further influence negative social interactions reported by the

caregiver. This finding is somewhat in line with the findings reported by Mavandadi and colleagues (2014), who found a significant relationship between patients' relationship quality and anxiety in caregivers.

Surprisingly, there were no significant partner effects found between negative interactions and caregiver burden. Previous research has suggested associations between negative social interactions and caregiver outcomes (Archbold et al, 1990; Lakey et al, 2002; Shim et al, 2011; Ricciardi et al, 2015;) but this again, is likely due to the caregivers in the current study not experiencing high levels of burden, as per the low means reported. Furthermore, no significant partner effects were found for the influence of mutuality on psychological and relationship functioning, or caregiver burden in the current study. The levels of burden in the current study are similar to those found in prior research by Leroi and colleagues (2012) who found burden to be similar in PD-N and PD-MCI caregivers. Considering MCI patients have relatively preserved executive functioning, as this is part of disease classification (Litvan et al, 2012; Wood et al, 2016), the assistance that they require from their caregivers may not yet be significant enough to influence negative caregiver outcomes as relationship mutuality has remained relatively high.

4.4 Clinical Implications

There are several ways in which this research has clinical implications. Firstly, health professionals and clinicians who work with PD patients and their caregivers should explore the quality of caregiving relationships in more depth. Due to the changes associated with PD, both physically and cognitively, role change within the dyad is likely to occur. This could happen in many ways but the main issue here is that an individual, who was once someone's husband or wife, is now their caregiver. With social interactions and mutuality influencing dyadic coping, understanding how patients and their spouses interact, and how they will

effectively cope with disease related changes together, will help to identify those at risk of negative outcomes in terms of psychological and relationship functioning.

Additionally, understanding how dyadic social interactions and psychological functioning influence relationship quality, can aid in developing relationship-focused interventions that provide patient-caregiver dyads with strategies that promote positive dyadic coping, which may result in better psychological and even disease outcomes for both patients and caregivers.

4.5 Strengths and Limitations

The use of a clinical sample of PD-MCI patients and their caregivers is a strength of the current research. With patients undergoing full neuropsychological and clinical assessment prior to being interviewed for the current study, it ensured that all patients met criteria for PD-MCI. The similarities between the current study and previous studies (Leroi et al, 2012; Jones, 2013) indicate that the current findings are generalizable to the greater PD-MCI population.

Another key strength of the current research is that structured interviews took place and both patients and caregivers were separated and asked questions by interviewers. This meant that both patients and caregivers were able to openly express their concerns or praise for the relationship without having their partner present. This also allowed for the reduction of missing data and errors, as interviewers filled in the questionnaires as the questions were asked. It is however, important to consider the influence of having the interviewer present, as this may have influenced the responses given by both patients and caregivers also.

Furthermore, both actor and partner effects were examined in the current study. Thus, outcomes for both patients and caregivers and how these potentially were related to the outcomes of the other spouse were assessed. This provides additional information on the extent to which perceived social support and psychological well-being were related to dyadic

coping. This is a major strength to the current research as there is only one other study (c.f Mavandadi et al, 2014) examining both actor and partner effects in PD patients.

The current study also has several limitations. There was no comparison group in the current study and therefore, the findings from the current research cannot be compared to PD-N and PD-D populations. With prior research suggesting differences in psychological functioning and caregiver outcomes across different stages of cognitive impairment in PD (Leroi et al, 2012; Jones , 2013; Szeto et al, 2016), it would be of interest to investigate dyadic interactions across patient groups to understand if social interactions manifest differently depending on disease stage. Another important consideration is to what extent these interactions are different from what occurs in healthy dyads, and comparing PD-MCI patient-caregiver dyads to healthy dyads would also provide a good comparison.

The sample size in the current study is also a limitation. With only 30 dyads being assessed, statistical power is an issue. This also meant that the complexity of the models that could be run to assess actor and partner effects were limited (for example, it would have been better to examine the influence of positive and negative interactions in one model instead of separate models). Additionally, gender imbalance was a limitation in the current study, with 80% of patients being male and thus, 80% of caregivers being female. The sample in the current study was too small to examine gender differences. This imbalance is reflective of the distribution of male/female patients in the wider PD population, with prevalence being higher in males (Wooten, Currie, Bovjberg, Lee & Patrie, 2004). However, it does mean that the findings of the current study are not necessarily generalizable to female patient-male caregiver dyads and future research should aim to recruit equal numbers of male and female patients and their caregivers.

Finally, since the current research is cross-sectional, we cannot formulate conclusions about cause and effect. This could mean that the direction of the relationships could be the

other way around; for example, the psychological functioning of patients and caregivers could be influencing the social interactions in the dyad, thus, psychological functioning was not assessed as a predictor variable in the current study although there could be effects of this on social interactions in the dyad. Additionally, prior relationship quality cannot be taken into account; thus, if there has already been a change in the relationship quality for patients and caregivers, this is not known due to only have post diagnosis ratings of relationship quality and therefore no comparison point.

4.6 Future Directions

There are a few adjustments that future research in PD-MCI patient-caregiver dyads might observe to improve the conclusions that can be drawn from the current study's findings. Firstly, a larger sample size would increase the statistical power and help to further understand how dyadic social interactions influence psychological well-being and relationship quality in these dyads.

Assessing patient-caregiver dyads longitudinally would allow for the evaluation of changes in psychological and relationship functioning to be addressed as disease progression occurs. With research suggesting that MCI predicts an increased risk to progress to dementia within 4 years (Dalrymple-Alford et al, 2011; Wood et al, 2016), it would be useful to further understand how social interactions change as PD progresses and how the nature of the relationship changes.

Furthermore, inclusion of all patient-caregiver dyads would also provide further evidence to generalize the influence of dyadic interactions in PD patients and their caregivers. The current study only assessed spousal dyads; however, family members and friends can often take on the role of the caregiver; therefore, including these would provide a comparison point to see how different types of dyadic coping influence both patient and caregiver outcomes.

4.8 Concluding Remarks

This research investigated the relationship between supportive and supportive dyadic interactions in PD-MCI patients and their caregivers and the potential influence these have on psychological and relationship functioning for both individuals. Previous studies established that disease related variables in PD influence individual outcomes in patients and caregivers; however, the current study took a dyadic approach in an attempt to understand how the interactions between individual outcomes may influence psychological and relationship functioning in the other spouse. Furthermore, the current research is the first to investigate these dyadic interactions in PD patients with MCI. This study provides preliminary support for identifying key variables associated with dyadic interactions and outcomes for PD patients and their caregivers. Findings from this study, and from future work in this area, may help inform interventions and health-care models that focus on positive interactions and dyadic coping, to maximize positive adjustment for both patients and their caregivers.

5 REFERENCES

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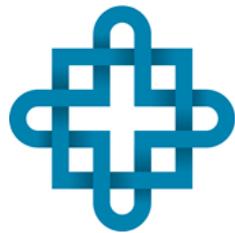
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APPENDIX A. Participant information sheet.



New Zealand Brain Research Institute

66 Stewart Street, Christchurch, New Zealand
Telephone 03 378 6347; Fax 03 378 6080

Progressive Changes of Potential Indicators in Parkinson's Disease

Information for Participants: "People with Parkinson's disease and their support person"

You have been invited to take part in this study because you are a participant or a support person of a participant in the study "Progressive changes of potential indicators in Parkinson's disease". The current study looks at how people with Parkinson's disease and their most important support person (such as a spouse/partner, family member) cope with the disease together and how it might influence the relationship between them. By taking part in this study you will help us find factors that influence the outcomes for both people affected by Parkinson's disease and their support person. We hope that the information we gather may help clinicians improve the quality of life of both the support person and the person affected by the disease.

Your participation is entirely voluntary (your choice) and additional to your participation in associated research. You can take as much time as you need to decide whether to take part. Maybe a friend, family member or whanau support can help you decide whether you want to participate in this study. The study staff are also available to answer any questions you may have before making a decision. If you decide not to take part, your continuing or future medical care will not be affected in any way.

Aim of the study

To learn how people with Parkinson's disease and their most important support person cope with the disease together and how it might influence their relationship.

Who will take part in the study?

Participants in the study are people with Parkinson's disease and their most important support person. The support person may or may not be living with the person with Parkinson's disease but does need to be directly involved with the person.

What is involved in taking part in the study?

You will complete a few brief questionnaires. You will also be videotaped discussing an imaginary trip to the supermarket or a visit to your wider family. These will be done once a year over the next three years. The interviews will be carried out either at the New Zealand Brain Research Institute or at the University of Canterbury and will take approximately one

hour to complete. You will be reimbursed with petrol vouchers should you choose to be interviewed at either location.

If you agree to participate, we will ask you questions about your experiences with coping with Parkinson's disease and how it might be influencing the relationship between you. By asking you these questions, we hope to identify issues that may help generate better outcomes for people with Parkinson's disease and for their support person. If you find that some questions raise negative emotions or memories, you may be directed to the appropriate services; brochures with relevant telephone numbers will be available if requested. If you give your consent, we will inform your G.P. of any potentially significant issues.

Potential risks of taking part in this research

There may be a slight risk of a heightened emotional reaction. In the event that either the person with Parkinson's disease or the support person shows any distress, the interview will only continue if both of you are able to do so.

The benefit of the study is that your experiences and opinion of coping with Parkinson's disease may be beneficial to others in the same situation.

Your Rights

Your participation is entirely voluntary. If you decide not to take part, your continuing or future medical care will not be affected in any way. If you do agree to take part, you are still free to withdraw from the study at any time, without having to give a reason.

Your results will be kept confidential. Your information will be coded by a number known only to the investigators. No material that could personally identify you will be used in any reports on this study. If you wish, we will send you a summary of the results of the study.

It may take some time for us to collect and analyse all of the data. The data will be stored securely for at least 10 years. The information gathered by Prof. Anderson and his team for this study may be useful for related research on Parkinson's disease in the future. If you decide to take part in this study you can also indicate whether you wish your information to be made available for future studies.

Concerns during the study

If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Advocate, telephone 03 377 7501 or (outside Christchurch) 0800 37 77 66.

Ethics

This project has received ethical approval from the Health and Disability Ethics Committees of the New Zealand Ministry of Health, ethics reference number URB/09/08/037. The investigator agrees to an approved auditor, appointed by the Ethics Committee or their approved representative, reviewing relevant medical records for the sole purpose of checking the accuracy of the information recorded for the study.

Participation

We appreciate the effort you would have to make to help us in our research. Our research grant does not allow us to provide cash to participants. However, you will be reimbursed for transport costs (e.g. taxi fares or petrol costs in the form of petrol vouchers) each time you attend a research session. Free car parking will be available.

Any questions or queries

If you have any questions, please phone Morgan McPhail on 027 767 0275 or send an email to her on morgan.mcphail@pg.canterbury.ac.nz

Contact details for the Principal Investigator

Professor Tim Anderson, University of Otago, phone (03) 378 6079.

Co-investigators:

Assoc. Prof. Roeline Kuijer, University of Canterbury
Morgan McPhail, University of Canterbury
Prof. John Dalrymple-Alford, University of Canterbury
Dr. Ross Keenan, Christchurch Radiology Group
Leslie Livingston, University of Otago
Dr. Michael MacAskill, University of Otago
Dr. Tracy Melzer, University of Otago
Dr. Toni Pitcher, University of Otago

APPENDIX B. Consent form completed by both patients and caregivers in the current study.



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CONSENT FORM

”People with Parkinson’s disease and their support person”

I have read and understood the information sheet dated 8th July 2015 for volunteers taking part in the study designed to gather data about how people with Parkinson’s disease and their most important support person (such as a spouse/partner, family member) cope with the disease together and how it might influence the relationship between them. I have had time to consider whether to take part. I have had the opportunity to discuss this study, and I am satisfied with the answers I have been given. I have had the opportunity to use whanau (family) support or a friend to help me ask questions and understand the study. I further understand that taking part in this study is completely voluntary (my choice) and that I may withdraw from participation in this study at any time, and this will in no way affect my future health care. I understand that participation in this study is confidential and that no material which could identify me will be used in any reports of this study. I know who to contact if I have any questions or problems about the study.

I consent to my GP being informed of my participation in this study.....YES/NO

I wish to receive a copy of the results.....YES/NO

Name of GP.....

I consent to the information gathered about me being used for future

research into studies related to Parkinson's disease (subject to ethical approval being given by a New Zealand Accredited ethics committee).....YES/NO

I wish to be part of the New Zealand Brain Research Institute's volunteer database.....YES/NO

I consent to the use of my data for future related studies, which have been given ethical approval from a Health & Disability Ethics Committee.....YES/NO

I(full name) hereby consent to take part in this study, and understand that by agreeing to be part of a volunteer database that I could be contacted again for another research study. I also understand that if I am contacted again, that I do not have to participate in that study.

Signature of Participant

Signature of witness

Project explained by

The following is the 2001 census form question about ethnicity. This data is collected for study demographics only

Researchers:

Morgan McPhail, Professor John Dalrymple-Alford, Associate Professor Roeline Kuijer, Leslie Livingston, Professor Tim Anderson

Which ethnic group do you belong to?
Mark the space or spaces that apply to you.

New Zealand European

Māori

Samoan

Cook Island Māori

Tongan

Niuean

Chinese

Indian

other (such as DUTCH, JAPANESE, TOKELAUAN). Please state:

Phone: 0277670275 (Morgan McPhail– Masters Student) Email: morgan.mcphail@pg.canterbury.ac.nz

APPENDIX C. UK Parkinson's Disease Society Brain Bank clinical diagnostic criteria. Adapted from Hughes, Daniel, Kilford & Lees, 1992.

UK Parkinson's Disease Society Brain Bank clinical diagnostic criteria

Step 1 Diagnosis of Parkinsonian syndrome

- Bradykinesia (slowness of initiation of voluntary movement with progressive reduction in speed and amplitude of repetitive actions)
- And at least one of the following:
 - Muscular rigidity
 - 4-6 Hz rest tremor
 - Postural instability not caused by primary visual, vestibular, cerebellar or proprioceptive dysfunction

Step 2 Exclusion Criteria for Parkinson's disease

- History of repeated strokes with stepwise progression of parkinsonian features
- History of repeated head injury
- History of definite encephalitis
- Oculogyric crisis
- Neuroleptic treatment at onset of symptoms
- More than one affected relative
- Sustained remission
- Strictly unilateral features after 3 years
- Supranuclear gaze palsy
- Cerebellar signs
- Early severe autonomic involvement
- Early severe dementia with disturbances of memory, language and praxis
- Babinski sign
- Presence of cerebral tumour or communicating hydrocephalus on CT scan
- Negative response to large doses of levodopa (if malabsorption excluded)
- MPTP exposure.

Step 3 Supportive prospective positive criteria for Parkinson's disease

(Three of more required for diagnosis of definite Parkinson's disease)

- Unilateral onset
- Rest tremor present
- Progressive disorder
- Persistent asymmetry affecting side of onset most
- Excellent response (70-100%) to levodopa
- Severe levodopa-induced chorea
- Levodopa response for 5 years or more
- Clinical course of 10 years or more

