Caregiving for Parkinson’s Disease Patients:
An Exploration of a Stress-Appraisal Model for Quality of Life and Burden

Belinda Goldsworthy
BA Behavioural Neuroscience University of Monash

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Supervisor: Dr Simon Knowles
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Declaration

“I declare that this report does not incorporate without acknowledgment any material previously submitted for a degree in any University, College of Advanced Education, or other educational institution, and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.”

“I further declare that the ethical principles specified in the policies and procedures of the Swinburne University Human Research Ethics Committee have been adhered to in the preparation of this report.”

Name: Belinda Goldsworthy

Signed: ___________________________

13th October 2006
Acknowledgments

Firstly, I would sincerely like to thank my supervisor, Simon Knowles, for his time, encouragement, patience, humor, and enthusiasm throughout the year. Thank you to Swinburne Alumni and Parkinson’s Victoria for their financial support for this project. I would particularly like to thank Glen Mahoney at Parkinson’s Victoria for facilitating the contact with the participants in this study and providing me with several resources on Parkinson’s disease. Also, thank you to all of the participants who completed the questionnaire. I greatly appreciate your time and effort and I sincerely hope that this research contributes to improving the lives of both Parkinson’s disease caregivers and the sufferers of Parkinson’s disease.

Finally, I would like to thank my friends for understanding the lack of time I have had for them this year. Most importantly, I would like to thank my family and boyfriend, James for the emotional support, encouragement, and belief in my ability. Lastly, I would especially like to thank my mum for the assistance she has given me throughout the year during the stressful times.
Abstract

Using an extension of Chappell and Reid’s (2002) stress-appraisal model, this study examined the relationships between a variety of caregiver stressors, appraisal, and protective factors associated with the burden and quality of life of Parkinson’s disease caregivers. A total of 136 Parkinson’s disease caregivers (39 males, 97 females; mean age= 64.59 years) participated in this study. Path analysis using Maximum Likelihood criterion, with Bollen-Stine bootstrap and standardised estimates was used to assess the model. Evaluation of the proposed model revealed that it was a good fit of the data. Supporting the hypotheses and Chappell and Reid’s (2002) model, were the findings that caree functional dependency and behavioural problems had an adverse impact on caregiver burden. In addition, caree functional dependency was found to be adversely related to caregiver quality of life. The results also found that frequency of breaks, perceived social support, and caregiver-caree relationship quality acted as protective factors of caregiver burden. Furthermore, the frequency of breaks acted as a protective factor of caregiver quality of life. This research provides an important contribution to a growing field of research applying theoretical models to investigate the stressors, appraisals, and protective factors that impact caregiver well-being.
Introduction

There has been a growing awareness that Parkinson’s disease can be physically and mentally disabling not only for the patient, but also for the caregiver (Aarsland, Larsen, Karlsen, Lim, & Tandberg, 1999; Caap-Ahlgren, Lena, & Ove, 2002; Chappell & Reid, 2002; Happe & Berger, 2002; E. Miller, Berrios, & Politynska, 1996; Teel & Press, 1999; Yates, Tennstedt, & Chang, 1999). Although caregiving has been reported as being a satisfying and positive experience (Davey, 2005; Rees, O’Boyle, & MacDonagh, 2001; Szmukler, Wykes, & Parkman, 1998), several studies have indicated that as the severity of Parkinson’s disease symptoms and level of care needed increase, so does the caregivers’ level of burden and health related symptoms (Carter et al., 1998; Davey, 2005; Koplas et al., 1999; Sheriff, 2005; Speer, 1993; Thommessen et al., 2002).

Caregiving has generated more interest among gerontologists than any other topic (George, 1990). However, despite the amount of research on caregivers and specifically on their burden, understanding of the relationship between the well-being of caregivers, caregiver stressors, and protective factors is not well understood. Although a great deal of research has been conducted on Parkinson’s disease, the majority of research has focused on the person with the disease, the disease process, and finding a cure for Parkinson’s disease (Carter et al., 1998; Marjama-Lyons & William, 2001).

To date, no study has assessed the overall impact of multiple disease-related and psychosocial factors on caregiver quality of life in a large
sample (Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006). In addition, very few studies have addressed the relationship between burden and well-being specifically in Parkinson’s disease caregivers. Consequently, several researchers have called for further research on the adverse health related consequences of caring for someone with Parkinson’s disease (Carter et al., 1998; Hirst, 2005; Hooker, Manoogian-O’Dell, Monahan, Frazier, & Shifren, 2000; Marjama-Lyons & William, 2001; Schrag et al., 2006) and the caregiver’s perspectives and outcomes (E. Miller et al., 1996; Yates et al., 1999).

The focus of this investigation will be to explore the relationships between a variety of stressors such as caree cognitive impairment, behavioural problems, and functional dependency as well as informal hours of caregiving on the well-being of Parkinson’s disease caregivers, specifically quality of life and burden. In addition, the protective factors associated with caregiver well-being will be investigated. These include; perceived social support, the frequency of breaks, formal service hours, caregiver self-esteem, and the quality of the caregiver-caree relationship.

A general summary of the characteristics of Parkinson’s disease and its impact on caregivers will now be undertaken.

*Parkinson’s disease*

Parkinson’s disease is a chronic progressive neurological disorder that ranks as the second most disabling of all chronic conditions (Anderson & Bury, 1988). The total number of people with Parkinson’s disease is four
times the number with Multiple Sclerosis, 40 times the number with Motor Neurone and Huntington’s disease, and 60 times the number with Muscular Dystrophy (Mahoney, 2006). Epidemiology statistics have indicated that there are currently around 80,000 Australians living with Parkinson’s disease. Within Victoria alone, reports indicate that around 20,000-25,000 individuals are affected. It is expected that on average, a further 1,000 individuals will be diagnosed with Parkinson’s disease within Victoria every year (Mahoney, 2006). Typically, it is a disease of aging with an onset after the age of 60 (Brod, Mendelsohn, & Roberts, 1998), however, up to 20% of cases are under the age of 50 when first diagnosed (Mahoney, 2006). It is also estimated that around 1.5 times more men are affected than women (Wooten, Currie, Bovbjerg, Lee, & Patrie, 2004).

Parkinson’s disease is caused by the degeneration of neuronal cells in the basal ganglia of the brain (particularly of the substantia nigra), resulting in a deficiency of dopamine, a neurotransmitter that controls movement (Marjama-Lyons & William, 2001). Once approximately 80% of the dopamine in the brain is lost, four classic symptoms are usually evident. These include; tremor, rigidity (stiffness), postural instability, and bradykinesia (slowness and poverty of movement) (Dakof & Mendelsohn, 1986). As a result of these symptoms, sufferers typically have less active and functional lives. Further exacerbating the difficulty of living with these symptoms is the fact that they constantly fluctuate on a daily and even hourly basis (Gunal, Nurichalich, Tuncer, Bekiroglu, &
Aktan, 2002). See Table 1 for a review of the physical and psychological symptoms of Parkinson’s disease.

Table 1.

*Summary of the Physical and Psychological Symptoms of Parkinson’s Disease.*

<table>
<thead>
<tr>
<th>Stage of Parkinson’s disease</th>
<th>Physical symptoms</th>
<th>Psychological symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early Stages (5-10 years).</td>
<td>Slowness in movement.</td>
<td>Anxiety.</td>
</tr>
<tr>
<td></td>
<td>Stiffness in movement.</td>
<td>Depression.</td>
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<tr>
<td></td>
<td>Tremor when a limb is relaxed (i.e. a slight tremor in one hand).</td>
<td>Irritability.</td>
</tr>
<tr>
<td></td>
<td>Some postural instability (i.e., unsteady on feet).</td>
<td>Lowered self-esteem.</td>
</tr>
<tr>
<td>Late stages (&gt;10 years).</td>
<td>Severe restrictions in movement (e.g., difficulty with simple motor tasks such as turning over in bed).</td>
<td>Loss of concentration.</td>
</tr>
<tr>
<td></td>
<td>Severe gait and postural disturbances (e.g., falls and a decrease in the ability to stand upright).</td>
<td>Depression.</td>
</tr>
<tr>
<td></td>
<td>Speech and swallowing disturbances.</td>
<td>Lowered self-esteem.</td>
</tr>
<tr>
<td></td>
<td>Problems with the automatic nervous system (e.g., constipation, decreased sexual libido).</td>
<td>Social inappropriateness.</td>
</tr>
<tr>
<td></td>
<td>Reduced facial expressions.</td>
<td>Poor planning and interpersonal problem solving.</td>
</tr>
<tr>
<td></td>
<td>Impairments in perceptual, visual, and spatial abilities.</td>
<td>Verbal perseveration.</td>
</tr>
<tr>
<td></td>
<td>Dementia (i.e., difficulty in tasks involving sequential steps, or activities which require short-term memory).</td>
<td>Difficulty generating novel ideas.</td>
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<td></td>
<td></td>
<td>Impaired working memory.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Speech monitoring deficits.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Personality changes (e.g., resistance to change and an inability to resist impulses).</td>
</tr>
</tbody>
</table>

*Note.* The summary of the physical and psychological symptoms of Parkinson’s disease was based upon the findings from Brod et al. (1998), Brown and Marsden (1990), Dakof and mendelsohn (1986), Marjama-Lyons and Williams (2001), and S.E. Starkstein and Marcelo (2002).
There is currently no cure for Parkinson’s disease, however several medications (e.g., Levodopa) act to increase dopamine levels and to control the physical symptoms in the short-term. However as the disease progresses, there is continued destruction of the cells in the basal ganglia resulting in a constant loss of dopamine. Consequently, in many cases, after ten years the therapeutic benefits of the medication do not outweigh the side effects (e.g., vomiting, hypotension, constipation, increased lethargy, and hallucinations) and the medication is discontinued (Marjama-Lyons & William, 2001).

Therefore, sufferers live with this disease for the rest of their lives (Dakof & Mendelsohn, 1986) and as the disease advances, patients become increasingly disabled, until eventually very little movement is possible (Brod et al., 1998). This places a high demand on the caregivers of people with Parkinson’s disease as their caree may be confined to a wheel-chair or bed and unable to speak or feed themselves (Marjama-Lyons & William, 2001).

**Parkinson’s disease and the demand for caregivers**

With an increasingly ageing society, the number of individuals who will be diagnosed with Parkinson’s disease is expected to double over the next 30 years, especially in developed countries (Brod et al., 1998; Caap-Ahlgren et al., 2002; Davey, 2005; Pepin, 2005). This will result in a corresponding increase in the number of Parkinson’s disease caregivers. According to Martinez-Martin et al. (2005), a caregiver is defined as “the
person who is usually cohabited with the patient and who is in some way
directly involved in the patient’s care or impacted by the patient’s health
problem” (p. 464).

As the symptoms of Parkinson’s disease increase, so does the level of
care required. This results in an increase in the physical and emotional
demands on the caregiver. Consequently, caregivers are the most vulnerable
yet valuable resource for the care of a patient with Parkinson’s disease
(Carter et al., 1998; Davey, 2005).

In the past, the majority of Parkinson’s disease patients were
hospitalised (E. Miller et al., 1996). However, previous research has
found that having a caregiver is associated with better outcomes in terms
of morbidity, mortality, and quality of life of the patient (Dickens et al.,
2004). Therefore, there is currently an increasing general emphasis on
community-based programs for the care of the elderly and most people
with Parkinson’s disease are looked after in the community (E. Miller et
al., 1996).

The impact of caregiving

Although providing care for those with a chronic and debilitating
disease (e.g., Alzheimer’s disease, Cancer, and Dementia, etc.) has been
reported as a satisfying positive experience (Davey, 2005; Rees et al.,
2001; Szmukler et al., 1998), research has consistently demonstrated the
role of several caregiver stressors that adversely impact a caregiver’s
psychological and physical health (Aarsland et al., 1999; Fried, Bradley,
According to Yates et al. (1999), a caregiver stressor is defined as “any agent that causes stress to the caregiver and develops secondary to caregiving within work and family roles” (p.14). These include; caree cognitive impairment (e.g., easily distractible, difficulty remembering time and dates, etc.), caree behavioural problems (e.g., hits, spits, kicks, bites, wanders during the day, etc.), and caree functional dependency (e.g., the amount of help required for eating, dressing, preparing meals, etc.).

Increases in caregiver stressors and informal hours of caregiving have been found to be adversely related to caregiver distress, depression, burden (e.g., strain and overload), perceived stress, physical health, and quality of life (e.g., spirituality, health, activity level, social support, resources, satisfaction with personal accomplishments, and life situations) (Aarsland et al., 1999; Chappell & Reid, 2002; Goode, Haley, Roth, & Ford, 1998; Hirst, 2005; Lawrence, Tennstedt, & Assmann, 1998; Martinez-Martin et al., 2005; B. Miller et al., 2001; Thommessen et al., 2002; Yates et al., 1999). Despite these findings, other researchers have found that caree behavioural problems and functional dependency are unrelated to caregiver depression, emotional distress, and burden (Aarsland et al., 1999; Zarit et al., 1980).

One reason for these inconsistent findings could be due to the fact that different caregiver groups were investigated by each study. For example,
Yates et al. (1999) investigated a non-specific population of caregivers, while Zarit et al. (1980) used a sample of Dementia caregivers. As found by Miller et al. (2001) and Thommessen et al. (2002), different caregiving factors are related to unique caregiver groups. See Table 2 for a summary of caregiver stressors and informal hours of caregiving and their relationship to caregiver well-being.
### Table 2.

**Summary of Caregiver Stressors and Informal Hours of Caregiving and their Relationship to Caregiver Well-being.**

<table>
<thead>
<tr>
<th>Author and date</th>
<th>Study focus</th>
<th>Subject characteristics</th>
<th>Type of study</th>
<th>Disease studied</th>
<th>Study conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Zarit, Reever, and Bach-Peterson (1980).</td>
<td>Factors related to the level of burden of caregivers.</td>
<td>29 Senile Dementia caregivers and their caregivers (average age of those with Dementia = 76).</td>
<td>Interview based.</td>
<td>Dementia.</td>
<td>The frequency of caree behavioural problems did not correlate with the level of caregiver burden. Based on these findings, the authors suggested that caree behavioural problems are distressing for caregivers but the ability of the caregiver to cope with the situation may depend on other factors (e.g., the amount of social support available to them).</td>
</tr>
<tr>
<td>Lawton et al. (1991).</td>
<td>A model of caregiving behaviours, evaluations of caregiving, and general psychological well-being.</td>
<td>529 caregivers of Alzheimer’s disease sufferers.</td>
<td>Interview based.</td>
<td>Dementia.</td>
<td>A decrease in the severity of caree symptoms was associated with an increase in the amount of help given by the caregiver, which in turn was associated with a decrease in caregiver burden and an increase in caregiver satisfaction. In addition, higher caregiver burden was adversely related to caregiver well-being (depression and positive affect).</td>
</tr>
<tr>
<td>Goode, Haley, Roth, and Ford (1998).</td>
<td>Changes in caregiving stressors, appraisals, coping responses, social support, and mental and physical health outcomes over one year.</td>
<td>122 Dementia patients and their caregivers</td>
<td>One year longitudinal study, questionnaire based.</td>
<td>Dementia.</td>
<td>Increases in caregiver stressors such as dealing with caree problem behaviours and changes in memory were adversely associated with caregiver depression and physical health.</td>
</tr>
</tbody>
</table>
Table 2. Summary of Caregiver Stressors and Informal Hours of Caregiving and their Relationship to Caregiver Well-being (continued).

<table>
<thead>
<tr>
<th>Author and date</th>
<th>Study focus</th>
<th>Subject characteristics</th>
<th>Type of study</th>
<th>Disease studied</th>
<th>Study conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Miller et al. (2001).</td>
<td>The relationship between stressors, social support, and caregiver distress.</td>
<td>496 Alzheimers disease caregivers, 412 family caregivers of those with Alzheimer’s, 293 caregivers who use formal/informal services, and 155 caregivers of elders.</td>
<td>Questionnaire based.</td>
<td>Alzheimer’s disease, elderly.</td>
<td>The number of caree behavioural problems was positively related to caregiver distress. However, when caregivers were compared in terms of what illness their caree had, different factors were associated with different caregiver groups. For example, there was a negative relationship between the use of formal services and caregiver distress for Alzheimer’s disease caregivers but for caregivers of elders there was no significant relationship.</td>
</tr>
<tr>
<td>Lawrence, Tennstedt, and Assmann (1998).</td>
<td>The processes through which quality of the relationship affects the linkages between caregiver stressors and caregiver well-being.</td>
<td>118 family caregivers of the elderly (elderly were aged 79-99).</td>
<td>Questionnaire based.</td>
<td>Elderly.</td>
<td>Increases in caregiver stressors such as dealing with caree behavioural problems was adversely associated with caregiver depression. However, the level of caree functional disability was not related to caregiver depression.</td>
</tr>
<tr>
<td>Yates, Tennstedt, and Chang (1999).</td>
<td>The relationship between caregiver stressors, protective factors, and caregiver well-being.</td>
<td>204 disabled elder caregivers and their carees (average age of caregivers=62).</td>
<td>Longitudinal study, interview based.</td>
<td>Elderly.</td>
<td>Caregivers who reported more caregiver stressors (i.e., caree cognitive impairment, functional dependency, and problem behaviours), reported more hours of caregiving and reported higher levels of depression.</td>
</tr>
</tbody>
</table>
Table 2. *Summary of Caregiver Stressors and Informal Hours of Caregiving and their Relationship to Caregiver Well-being (continued).*

<table>
<thead>
<tr>
<th>Author and date</th>
<th>Study focus</th>
<th>Subject characteristics</th>
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<th>Disease studied</th>
<th>Study conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chappell and Reid (2002).</td>
<td>The relationship between caregiver burden and well-being.</td>
<td>294 caregivers of the elderly and those with a variety of illnesses.</td>
<td>Interview and questionnaire based.</td>
<td>Elderly.</td>
<td>Caregiver well-being was directly influenced by informal hours of caregiving. Lower caregiver burden scores and less hours of informal caregiving led to higher caregiver well-being. However, increased informal hours of care led to higher caregiver burden. An increase in caree behavioural problems also led to higher caregiver burden.</td>
</tr>
<tr>
<td>Hirst (2005).</td>
<td>Individual change in psychological distress of caregivers.</td>
<td>5000 caregivers of a variety of illnesses and their carees.</td>
<td>Questionnaire and interview based.</td>
<td>Variety of illnesses.</td>
<td>The risk for the onset of distress in caregivers increases progressively with the number of hours of caregiving. Specifically, caregivers providing longer hours of care presented higher levels of distress, women more so than men.</td>
</tr>
<tr>
<td>Aarsland et al. (1999).</td>
<td>Emotional and social distress in Parkinson’s disease caregivers.</td>
<td>94 Parkinson’s disease caregivers and patients, 100 Diabetes mellitus patients and caregivers, and 98 healthy well-functioning elderly patients in the control group.</td>
<td>Interview and questionnaire based.</td>
<td>Parkinson’s disease, Diabetes mellitus.</td>
<td>Caree functional impairment exacerbated caregiver stress but not emotional distress. Both cognitive impairment and behavioural disturbances of the caree contributed to an increase in caregiver emotional distress.</td>
</tr>
</tbody>
</table>
Table 2. Summary of Caregiver Stressors and Informal Hours of Caregiving and their Relationship to Caregiver Well-being (continued).

<table>
<thead>
<tr>
<th>Author and date</th>
<th>Study focus</th>
<th>Subject characteristics</th>
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<th>Disease studied</th>
<th>Study conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thommessen et al. (2002).</td>
<td>Factors related to the psychosocial burden of spouse caregivers.</td>
<td>Data on patient-spouse couples came from three previously published studies; 36 Stroke patient-spouse couples (Thommessen et al., 2002), 58 Parkinson’s disease patient-spouse couples (Aarsland et al., 1999), and 92 patients with Dementia and their caregivers (Braekhus, Oksengaard, Engedal, &amp; Laake, 1998).</td>
<td>Interview and questionnaire based.</td>
<td>Stroke, Parkinson’s disease, Dementia.</td>
<td>There was a negative relationship between caree cognitive function and psychosocial burden of spouse caregivers of patients with Stroke or Parkinson’s disease. However, only a weak association was identified in caregivers of patients with Dementia. The psychosocial burden of caregivers was also negatively related to caree functional dependency in patients with Parkinson’s disease and Dementia.</td>
</tr>
<tr>
<td>Martinez-Martín et al. (2005).</td>
<td>The impact of Parkinson’s disease on informal caregivers and the main factors influencing caregiver strain.</td>
<td>64 Parkinson’s disease patient-caregiver pairs.</td>
<td>Questionnaire based.</td>
<td>Parkinson’s disease.</td>
<td>A lower perceived quality of life was found in caregivers who cared for those with more severe functional disability.</td>
</tr>
</tbody>
</table>
Several protective factors (i.e., any agent that reduces the risk of the adverse physical and psychological health effects of caregiving) have been identified as to ameliorate the adverse effects of caregiving. These include: perceived social support (Chappell & Reid, 2002; Goode et al., 1998; Haley, Levine, Brown, & Bartolucci, 1987; E. Miller et al., 1996; Pagel & Becker, 1987), the frequency of breaks (Chappell & Reid, 2002), caregiver self-esteem (Chappell & Reid, 2002; Pagel & Becker, 1987; Talkington-Boyer & Smith, 1994), and the quality of the caregiver-caree relationship (i.e., perceived cohesion and satisfaction) (Beeson, Horton-Deutsch, Farran, & Neundorfer, 2000; Chee & Mancini, 2002; Fried et al., 2005; Heru, Ryan, & Iqbal, 2004; Scharlach, 1987; Williamson & Shulz, 1990; Yates et al., 1999).

According to a number of independent researchers (Chappell & Reid, 2002; Tennstedt, Crawford, & McKinlay, 1993; Yates et al., 1999) other protective factors such as formal service use (i.e., the number of hours that the caregiver receives services inside or outside of the home such as respite, home cleaning services, etc.) have no direct relationship with caregiver burden, depression, overload, and well-being. Instead, formal service use may be part of the caregiving lifestyle and contribute towards maintaining the level of well-being of caregivers (Chappell & Reid, 2002; Tennstedt et al., 1993). See Table 3 for a summary of protective factors and their relationship to caregiver well-being.
Table 3.

**Summary of Protective Factors and their Relationship to Caregiver Well-being.**

<table>
<thead>
<tr>
<th>Author and date</th>
<th>Study focus</th>
<th>Subject characteristics</th>
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<th>Disease studied</th>
<th>Study conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Haley, Levine, Brown, and Bartolucci (1987).</td>
<td>Factors related to life satisfaction and health outcomes among Dementia caregivers.</td>
<td>54 family caregivers of Dementia patients.</td>
<td>Interview and questionnaire based.</td>
<td>Dementia.</td>
<td>Higher levels of social network size, activity, and network satisfaction was positively related to caregiver life satisfaction and health. Individual differences in social support and activity accounted for the greatest amount of variance in life satisfaction.</td>
</tr>
<tr>
<td>Pagel and Becker (1987).</td>
<td>The relationship between caregiver social support, self-esteem, and depression.</td>
<td>68 spouse caregivers of patients with Alzheimer’s disease (25 male and 43 female) (aged 37-85 years).</td>
<td>Interview based.</td>
<td>Alzheimer’s disease.</td>
<td>The perceived level of social support and self-esteem of caregivers was negatively associated with caregiver depression. Various complex interactions were found between self-esteem, depression, and social support that contributed to predicting depression in response to a stressor.</td>
</tr>
<tr>
<td>Willamson and Schulz (1990).</td>
<td>The effects of the quality of the caregiver-caree relationship on distress among Alzheimer’s disease caregivers.</td>
<td>174 caregivers of Alzheimer’s disease patients who were non-institutionalised.</td>
<td>Interview based.</td>
<td>Alzheimer’s disease.</td>
<td>Among men, having a poorer caregiver-caree relationship prior to disease onset was associated with higher levels of caregiver depression. Among women, having a closer relationship with the caree prior to disease onset was associated with higher levels of caregiver depression. For both male and female caregivers, having a closer relationship prior to illness onset was related to lower burden.</td>
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<td>Goode, Haley, Roth, and Ford (1998)</td>
<td>Changes in caregiving stressors, appraisals, coping responses, social support, and mental and physical health over a one year period.</td>
<td>122 patients with dementia and their caregivers.</td>
<td>Longitudinal study, questionnaire based.</td>
<td>Dementia.</td>
<td>Initial social support showed a significant negative relationship with changes in health symptoms indicating a protective role of social support. Those caregivers who reported higher initial levels of social support showed improved health over time.</td>
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<td>Heru, Ryan, and Iqbal (2004).</td>
<td>The relationship between family functioning and caregiver burden.</td>
<td>38 caregivers of those with Dementia (61% were spouses).</td>
<td>Questionnaire based.</td>
<td>Dementia.</td>
<td>A negative relationship was found between family functioning and caregiver strain and burden. The authors suggested that communication is significantly disturbed in caregivers experiencing high burden.</td>
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<td>Scharlach (1987).</td>
<td>The role of the quality of the caregiver-caree relationship on caregiver strain.</td>
<td>37 female caregivers of their elderly mothers. The elderly mothers ranged in age from 69-92 years old.</td>
<td>Questionnaire based.</td>
<td>Elderly.</td>
<td>The caregivers who experienced greater burden reported poorer relationships with their mothers. Higher caregiver-caree relationship quality was also negatively associated with caree loneliness.</td>
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<tr>
<td>Tennstedt, Crawford, and McKinlay (1993).</td>
<td>The substitution of formal long-term services for informal care.</td>
<td>5,855 caregivers of the elderly (the elderly were all aged over 70 years).</td>
<td>Seven year longitudinal study, questionnaire based.</td>
<td>Elderly.</td>
<td>Formal service use did not reduce the amount of informal care provided by caregivers but rather supplemented the care. Therefore, formal service use may not substitute for informal care but as the needs for care increase, it maintains the continuity of care and the caregiver’s well-being and level of burden.</td>
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<td>Yates, Tennstedt, and Chang (1999).</td>
<td>The relationship between caregiver stressors, protective factors, and caregiver well-being.</td>
<td>204 disabled elder caregivers and their carees (average age of caregivers=62).</td>
<td>Longitudinal study, interview based.</td>
<td>Elderly.</td>
<td>The quality of the caregiver-caree relationship was negatively associated with caregiver depression and overload. Perceived emotional support of the caregiver was also negatively associated with caregiver depression. It was also found that increased formal service use did not reduce caregiver overload or depression.</td>
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<td>Chappell and Reid (2002).</td>
<td>The relationship between caregiver burden and well-being.</td>
<td>294 caregivers of the elderly and those with a variety of illnesses.</td>
<td>Interview and questionnaire based.</td>
<td>Elderly.</td>
<td>Caregiver well-being (i.e., life-satisfaction) was positively related to self-esteem and perceived social support. In addition, caregiver self-esteem was more strongly related to well-being than to burden. An increase in the frequency of breaks from caregiving was associated with an increase in the number of informal hours of caregiving, which in turn was associated with an increase in caregiver burden and a decrease in caregiver well-being. Formal service use had no significant effect on caregiver burden or well-being.</td>
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<tr>
<td>Fried, Bradley, O’Leary, and Byers (2005).</td>
<td>The relationship between the communication needs of caregivers and caregiver burden.</td>
<td>226 older people (aged over 60) with potentially limited life expectancies and their caregivers.</td>
<td>Interview based.</td>
<td>Elderly.</td>
<td>Caregivers who desired more communication with their carees had significantly higher burden scores than caregivers who did not. However, overall the level of emotional burden reported by the caregivers was low.</td>
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<td>Chee and Mancini (2002).</td>
<td>The long term effects of marital quality on the caregivers’ commitment to their relationship with the caree and to their level of depression.</td>
<td>Spousal caregivers for a variety of illnesses. The number of caregivers is unknown.</td>
<td>Questionnaire based.</td>
<td>Variety of illnesses.</td>
<td>Caregivers who reported a higher quality of relationship with their caree were less likely to report depression and saw themselves as having a higher moral commitment towards their partner.</td>
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<td>Miller, Berrios, and Politynska (1996).</td>
<td>The impact of caregiver social support on caregiver distress.</td>
<td>54 married Parkinson’s disease sufferers and their caregivers and 36 married control subjects and their partners where both partners were in good health.</td>
<td>Interview based.</td>
<td>Parkinson’s disease.</td>
<td>The size of the social network did not predict caregiver distress. However, many of the contacts were casual contacts and it was family members who appeared to form the vast majority of long-term intimate relationships with the caregiver of the kind needed to provide useful support. These results suggested that it may not be a matter of how many contacts the caregiver has but that their level of perceived social support plays an important protective role for the adverse effects of caregiving.</td>
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As outlined in Tables 2 and 3, an increasing amount of research has explored the stressful consequences of caregiving and the factors that offset and protect against those negative consequences. However, several researchers (Lawrence et al., 1998; B. Miller et al., 2001; Pagel & Becker, 1987; Spruytte, Audenhove, Lammertyn, & Storms, 2002) have argued that more complex theoretical models which incorporate linkages between the caregiver stressors, appraisals, protective factors, and their interactions are required. A review of the current theoretical models exploring caregiver well-being will now be undertaken.

Models of caregiver well-being

Several researchers (Chappell & Reid, 2002; Goode et al., 1998; Lawrence et al., 1998; M.P Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Yates et al., 1999) have attempted to develop and evaluate theoretically based models to explain the relationships between caregiver stressors, protective factors, and caregiver outcomes. These models aim to explain the relationships between individual and environmental factors (e.g., caregiver age, informal hours of caregiving, etc.), mediators (e.g., caregiver self-esteem), and their impact on aspects of caregiver well-being (e.g., depression and strain). To date, the majority of caregiver models developed have been based on either stress or appraisal theory-based models.

Stress based models focus on identifying stressors, mediators, and their impact on caregiver well-being (Whitlatch et al., 2001). This theoretical
approach proposes that there are a range of stressors related to caregiving, and that these stressors are influenced by a variety of contextual characteristics (e.g., age, gender, etc.) associated with the caregiver and the caree. Together these stressors and contextual factors can proliferate to such an extent that they produce negative outcomes such as caregiver stress and a decrease in caregiver well-being (Whitlatch et al., 2001).

According to Whitlatch et al. (2001), stress models are broad in scope and dynamic in nature, making them easily adaptable to test the course of stress for caregivers in a variety of situations. However, they have been criticised as they do not take environmental and psychosocial factors (e.g., informal hours of caregiving) into account.

In contrast to the stress model approach, the appraisal model, has attempted to account for the relational aspect. The appraisal model views the caregiving situation as a dynamic process that involves caregivers, care receivers, and other environmental and psychosocial factors (Yates et al., 1999). It groups subjective and interpretive variables (e.g., caregiver burden, overload, informal hours of caregiving, etc.) into the category of “appraisal” and adds this appraisal factor to the basic stress model. According to Yates et al. (1999), caregiver appraisal variables commonly influence the relationship between primary stressors and the outcome.

One advantage of the appraisal model is that it provides clearer boundaries between the stages of the stress process, making the model more accurate temporally (Braithwaite, 1996). In addition, the appraisal model controls for environmental and psychosocial factors (Yates et al.,
However, according to Yates et al. (1999), although this theoretical approach attempts to improve on several limitations of the stress model approach, it has been criticised for several reasons.

The main limitation of this model is that the components of the appraisal overlap with components of resources and coping strategies (Yates et al., 1999). Furthermore, as stress and appraisal models often consider caree characteristics to be stressors, they fail to account for the dyadic relationship between the caregiver and the caree (Braithwaite, 1996; Yates et al., 1999). In addition, although these models are prevalent in research and varied in their applications, individually they fail to account for many of the complex relationships that exist between caregiver stressors, appraisals, protective factors, and caregiver well-being (Fried et al., 2005; B. Miller et al., 2001; Spruytte et al., 2002; Zarit et al., 1980). Therefore, more complex models that combine both the stress and appraisal model and incorporate the caregiver-caree relationship are required.

Integration of stress and appraisal models to predict caregiver well-being: A stress-appraisal model

Caregiving research has been criticised for underemphasising the importance of the complex relationships between stressors, protective factors, and appraisal variables (Lawrence et al., 1998; B. Miller et al., 2001; Pagel & Becker, 1987; Spruytte et al., 2002). To progress beyond
this limitation, this section describes a more integrated model of caregiver well-being by linking stress and appraisal models.

Stress and appraisal models of caregiver well-being are closely related (Yates et al., 1999). Therefore, by using a stress-appraisal model many additional and more complex relationships between caregiver stressors, protective factors, appraisal, and caregiver well-being can be established. For example, a number of independent researchers (Chappell & Reid, 2002; Goode et al., 1998; Yates et al., 1999) have found complex mediating and moderating relationships of caregiver well-being and burden. In addition, by including aspects of both stress and appraisal models, the limitations that exist when these models are used individually, may be overcome or reduced.

Due to the importance and advantages of identifying both stressors and their appraisal (Kinsella, Cooper, Picton, & Murtagh, 1998), Yates et al. (1999) developed a conceptual model based on the stress model by Pearlin, Mullan, Semple, and Skaff (1990) and an appraisal model by Lawton, Kleban, Moss, Rovine, and Glicksman (1989). See Figure 1 for Yates et al.’s (1999) conceptual model of caregiver well-being.
Figure 1. Yates et al.’s (1999) conceptual model of caregiver well-being.
Using a sample of 204 caregivers to evaluate their model, Yates et al. (1999) found that higher levels of caregiver stressors such as caree cognitive impairment, behavioural problems, and functional dependency were adversely associated with caregiver depression. This relationship was mediated by caregiver-caree relationship quality, caregiver emotional support, and caregiver mastery (i.e., positive view of one’s ability to cope). Specifically, caregivers of those with more behavioural problems were more likely to have a poorer quality of relationship with their caree and those who had a poorer quality of relationship with their caree were likely to report greater levels of overload and were at greater risk of depression. In addition, Yates et al. (1999) found that regardless of the level of primary stressors, caregivers with higher levels of emotional support were at lower risk of depression.

Prior to Yates et al. (1999) research, the primary and secondary appraisals had not been examined as part of the same model and caregiver research was based on either stress or appraisal models. However, Yates et al.’s (1999) findings suggested many advantages of investigating both the impact of stressors as well as the appraisal of these stressors on caregiver well-being. In spite of these advantages, Yates et al.’s (1999) research was limited to only one aspect of caregiver well-being (depression). According to Yates et al. (1999), further research was required using the model to determine how the factors contribute to the overall well-being of caregivers.
In a more recent study by Chappell and Reid (2002), Yates et al.’s (1999) conceptual model was applied to predict burden and well-being (life satisfaction) in caregivers of the elderly. Chappell and Reid (2002), aimed to extend Yates et al.’s (1999) measure of well-being by measuring caregiver life satisfaction in seven essential areas of a caregiver’s life (i.e., health, finances, housing, partner, recreation, religion, and transportation).

Several additional variables were also included, such as caregiver self-esteem and the frequency that caregivers received breaks. Based on previous research, Chappell and Reid (2002) argued that the frequency of breaks and self-esteem were two important protective factors that had not been previously investigated using a stress-appraisal model.

According to Chappell and Reid’s (2002) model, caregiver well-being (i.e., life satisfaction) and burden are influenced by both stressors, appraisal relating to the stressors, and mediators. See Figure 2 for Chappell and Reid’s (2002) conceptual model of caregiver well-being.
Figure 2. Chappell and Reid’s (2002) conceptual model of caregiver well-being.
Chappell and Reid (2002) found several complex relationships between caregiver stressors, informal hours of caregiving, protective factors, and caregiver well-being. An increase in the frequency of breaks from caregiving was associated with an increase in the informal hours of caregiving, which in turn was associated with an increase in caregiver burden and a decrease in caregiver well-being. However, a higher frequency of caregiver breaks was also associated with an increase in caregiver self-esteem and led to lower caregiver burden.

Among the four mediators proposed (formal service hours, self-esteem, frequency of breaks, perceived social support), only perceived social support acted as a mediator between the caregiver stressors and caregiver well-being. Perceived social support was directly and positively influenced by caree functional dependency and an increase in perceived social support was associated with an increase in caregiver well-being.

While formal service use did not act as a mediator between the primary stressors and caregiver well-being, it was directly and positively related to caree functional dependency and negatively influenced by caree cognitive status. Caregivers of those with greater functional dependency, tended to use more formal service hours and caregivers of those with Dementia or other serious memory problems reported using less hours of formal service. The limitations of this model will now be reviewed.
Limitations of Chappell and Reid’s (2002) model of caregiver well-being

Although Chappell and Reid (2002) aimed to extend and improve on Yates et al.’s (1999) well-being measure, their measure was limited to one domain of caregiver well-being (i.e., life satisfaction). However, it is well recognised that there are a number of adverse health related consequences of caregiving (e.g., depression, stress, and loneliness) (Aarsland et al., 1999; Ellgring, 1999; Happe & Berger, 2002; Marjama-Lyons & William, 2001; E. Miller et al., 1996; Teel & Press, 1999; Thommessen et al., 2002). Therefore, a more diverse measure of well-being that includes professional, social, and leisure aspects is necessary for future research.

In addition, Chappell and Reid’s (2002) measure of well-being (The Andrews and Withey Life Satisfaction scale) was a non-specific measure, rather than a measure specifically for caregivers. Consequently, this measure may have failed to consider several important aspects that may influence a caregiver’s well-being, such as the lack of support from other family members, and the lifestyle changes that they have had to make.

Chappell and Reid’s (2002) measures of burden and caree cognitive impairment have also been criticised. Although it is well recognised that burden is a multidimensional construct, Chappell and Reid (2002) used a unidimensional measures to assess caregiver burden; the Zarit Caregiver Burden Inventory (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005; Chappell & Reid, 2002; Fried et al., 2005; Thommessen et al., 2002). The Zarit Caregiver Burden Inventory (Zarit et al., 1980) includes common areas of concern for the caregiver such as health, finances, social life, and
interpersonal relations. However, burden is recognised as a multidimensional construct and by limiting measures to a small number of aspects, a complete and accurate assessment of caregiver burden may not be obtained. Other more subjective qualities may also be relevant to caregiver burden, such as restrictions on the caregiver’s time, caregiver’s feelings of missing out on life, and the caregiver’s negative feelings towards their caree.

Chappell and Reid’s (2002) measure of caree cognitive impairment was also limited as this measure failed to take specific aspects of caree cognitive impairment (e.g., impaired attention span, impaired ability to make routine decision, impaired impulse control, etc.) into account. Participants were required to indicate whether their caree had Alzheimer’s disease, other Dementia, or other serious memory loss problems. However, it is possible that a caree did not have Dementia or any of these symptoms but they still had some form of cognitive impairment.

In addition, complementary to Yates et al.’s (1999) research, Chappell and Reid (2002) focused on a population of caregivers who care for those with a variety of chronic illnesses. However, different caregiver outcomes have been found for different disorders (Hooker et al., 2000; B. Miller et al., 2001; Thommessen et al., 2002). Therefore it would be beneficial to investigate the adverse impact of caregiving using a specific population of caregivers, such as Parkinson’s disease caregivers.

Lastly, Chappell and Reid (2002) failed to incorporate the quality of the caregiver-caree relationship as a protective factor of caregiver well-
being. However, there is substantial evidence (Beeson et al., 2000; Chee & Mancini, 2002; Fried et al., 2005; Scharlach, 1987; Williamson & Shulz, 1990; Yates et al., 1999) that indicates that an increase in the quality of the caregiver-caree relationship is advantageously related to caregiver depression, burden, life satisfaction, and physical health.

**Aims**

Using an extension of Chappell and Reid’s (2002) stress-appraisal model this study aimed to investigate the relationships between caregiver stressors (i.e., cognitive impairment, behavioural problems, and functional dependency of the caree) as well as informal hours of caregiving and their impact on the burden of Parkinson’s disease caregivers. In addition, this study will explore the protective role of perceived social support, frequency of breaks, formal service hours, self-esteem, and quality of the caregiver-caree relationship for caregiver burden.

Addressing the limitations of Chappell and Reid (2002) who used unidimensional measures of caregiver well-being (i.e., life satisfaction), this study also aimed to investigate the relationships between caregiver stressors (i.e., caree cognitive impairment, behavioural problems, and functional dependency) as well as informal hours of caregiving and their impact on the quality of life of Parkinson’s disease caregivers. Furthermore, the current study will explore the protective role of perceived social support, frequency of breaks, formal service hours, self-
esteem, and quality of the caregiver-caree relationship for caregiver quality of life.

This study also aimed to address other limitations of Chappell and Reid’s (2002) research, by using a specific measure of quality of life for Parkinson’s disease caregivers ((the Scale of Caregiver Quality of Life (SQLC)). In addition, this study aimed to improve on Chappell and Reid’s (2002) measure of caregiver burden and caree cognitive impairment by using the Caregiver Burden Inventory (CBI), a multidimensional measure assessing the impact of burden on caregivers and a Modified Mental Status Examination, respectively.

Finally, based on previous research (Chee & Mancini, 2002; Lawrence et al., 1998; Scharlach, 1987; Williamson & Shulz, 1990; Yates et al., 1999), this study aimed to extend Chappell and Reid’s (2002) stress-appraisal model by investigating the additional protective factor of the quality of the caregiver-caree relationship on caregiver burden and quality of life. See Figure 3 for the proposed stress-appraisal model of caregiver well-being based on Chappell and Reid’s (2002) model.
Figure 3. The proposed stress-appraisal model of caregiver well-being based on Chappell and Reid’s (2002) model.
Hypotheses

Based on previous research (Aarsland et al., 1999; Chappell & Reid, 2002; Goode et al., 1998; Hirst, 2005; Lawrence et al., 1998; M.P Lawton et al., 1991; B. Miller et al., 2001; Thommessen et al., 2002; Yates et al., 1999), it was hypothesised that increased caregiver stressors (i.e., caree cognitive impairment, behavioural problems, and functional dependency) as well as increased informal hours of caregiving would be adversely related to caregiver burden.

Secondly, based on previous research (Chappell & Reid, 2002; Chee & Mancini, 2002; Fried et al., 2005; Goode et al., 1998; Haley et al., 1987; Heru et al., 2004; Lawrence et al., 1998; Pagel & Becker, 1987; Scharlach, 1987; Talkington-Boyer & Smith, 1994; Williamson & Shulz, 1990; Yates et al., 1999), it was hypothesised that perceived social support, the frequency of breaks, formal service hours, and self-esteem would act as protective factors ameliorating the adverse effects of Parkinson’s disease on caregiver burden.

Extending upon Chappell and Reid’s (2002) unidimensional measure of caregiver well-being (i.e., life satisfaction), it was also hypothesised that increased caregiver stressors (i.e., caree cognitive impairment, behavioural problems, and functional dependency) as well as increased informal hours of caregiving would be adversely related to caregiver quality of life. Furthermore, it was hypothesised that perceived social support, the frequency of breaks, formal service hours, and self-esteem would act as
protective factors ameliorating the adverse effects of Parkinson’s disease on
caregiver quality of life.

Lastly, further extending upon Chappell and Reid’s (2002) model, it was
hypothesised that the quality of the caregiver-caree relationship would act
as a protective factor ameliorating the adverse effects of Parkinson’s
disease on caregiver burden and quality of life.
Method

Participants

A total of 136 Parkinson’s disease caregivers participated in the study. Thirty-nine were male (28.7%) and 97 female (71.3%). The youngest participant was 35 years old and the oldest was 83 years old ($M=64.59$, $SD=11.26$). Three participants did not report their age. Eighty-nine point seven percent were currently in a long term relationship averaging 37.22 years ($SD=15.14$). Of the participants without partners, 6.6% of the total sample identified themselves as single, 1.5% as divorced, and 2.2% as widowed.

The majority of caregivers were married to their caree (81.6%), 2.9% were friends, .7% were brother or sister, and 14.7% reported that their relationship with their caree was of a different nature (e.g., cousin, niece, etc.). Given the high number of caregivers who were married to their caree, it is not surprising that 88.2% lived in the same house as their caree, 4.4% in another suburb or city, 2.9% within walking distance, 2.2% within the same city/suburb, .7% in a household connected to their caree, and 1.5% in another arrangement (e.g., in a nursing home). On average, caregivers had known their caree for 44.23 years ($SD=14.58$) and had been caring for them for 8.29 years ($SD=9.57$). In the week prior to completing the questionnaire, caregivers had provided care for an average of 66.96 hours ($SD=61.07$).

The mean number of years since Parkinson’s disease symptoms were first noticed in the caree was 11.18 years and on average it had been 9.29 years since they were diagnosed. The majority of carees (57.4%) had other
medical conditions as well as Parkinson’s disease (e.g., Heart disease and Glaucoma). In addition, 42.6% of caregivers identified themselves as having a serious medical condition such as Diabetes and Arthritis.

A total of 64% of the participants were not working. However 22.1% of the participants were paid for caregiving. Those who worked outside of caregiving worked an average of 9.31 hours a week ($SD=15.53$).

Educational levels varied amongst participants; 17.6% had obtained postgraduate qualifications, 25.7% completed tertiary studies, 11.8% had a trade qualification, 16.9% completed secondary education, 25.7% had some secondary education, and 2.2% indicated that the highest educational level they had achieved was primary. The majority were born in Australia (66.2%) and currently resided in Australia (89%), and only 6.6% reported a first language other than English.

Participants were recruited using two methods. A total of 360 questionnaires were mailed to members of Parkinson’s Victoria whose names and addresses had been provided by the organisation as potential participants. One hundred and thirty four questionnaires were returned by mail. This represented a response rate of 37.22%. Nineteen questionnaires were returned blank with a note indicating that the recipient was not a caregiver and therefore was unable to participate. This resulted in a total of 115 questionnaires from this source.

Participants were also obtained by posting information about the research on the Villa Maria Disability Services, Parkinson’s Association of Victoria, South Australia, and New South Wales web-pages and on a
number of Parkinson’s disease newsgroups and forums on the Internet. This resulted in a further 21 completed questionnaires making a total of 136 completed surveys. There was no significant difference in the demographics of people recruited through Parkinson’s Victoria and those recruited online.

Materials

The questionnaire consisted of demographic as well as caregiver and caree related questions and used established scales with tested validity and reliability (see Appendix A for study questionnaire).

Demographic questions. Demographic questions related to the caregiver’s age, gender, marital status, length of relationship with the caree, place of birth, first language, work status, medical conditions, and education. The caregiver was also asked questions associated with the length of time that they have been caregiving, how long they have known the caree, and how close they live to the caree.

Caree cognitive impairment. Caree cognitive impairment was measured using a modified version of the Mental Status Examination (Crary & Johnson, 1981). The original Mental Status Examination consists of 58 items and five subscales relating to aspects of psychiatric functioning such as appearance, behaviour, feeling (affect and mood), perception, and
thinking. The original scale has been found to be highly reliable (Cronbach’s alpha well above .80) (Groth-Marnat, 2003).

For the purpose of this study, the Mental Status Examination was modified to include only the thinking section (14 items). In addition, with the assistance of a senior counselling psychologist (R. Cook, Swinburne University), further adjustments were made to aid the understanding of each item. For example, ‘Disorientation on place’ was accompanied by ‘Fails to remember places and directions’.

Item statements were assessed by the participants using a dichotomous scale where 0=Absent and 1=Present. Based on Crary and Johnson (1981), an overall score for the level of caree cognitive impairment was obtained by the sum of all items. The theoretical range for this scale was 0-14; higher scores indicated more caree cognitive impairment. For the present study, the Cronbach’s alpha reliability for the Modified Mental Status Examination was .90, indicating high internal consistency.

Caree behavioural problems. Caree behavioural problems were measured using the Behavioural Problems Scale (Chappell & Reid, 2002). Statements were assessed by participants as to how often particular behaviours were displayed by their caree. The scale is a 5-point Likert scale where 0=Never, 1=Rarely, 2=Sometimes, 3=Frequently, and 4=All the time. Examples of items are ‘Wanders during the night’, ‘Makes physical attacks’, and ‘Requires constant supervision or direction’.
Based on Chappell and Reid (2002), an overall score of the frequency of caree behavioural problems was the sum of all 10 items. The theoretical range for this scale is 0-40; higher scores indicated that caree behavioural problems occurred more frequently. This scale has been found to be reliable (Cronbach’s alpha of .66) (Chappell & Reid, 2002). For the present study, the Cronbach’s alpha reliability for the Behavioural Problems Scale was .83, indicating high internal consistency.

*Caree functional dependency.* Caree Functional dependency was measured using a combined scale of the Activities of Daily Living Scale (ADL) (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) and the Instrumental Activities of Daily Living Scale (IADL) (M.P. Lawton & Brody, 1969). The ADL includes basic activities of hygiene and personal care and the IADL is comprised of activities necessary to reside in the community such as shopping, managing finances, housekeeping, and meal preparation.

A total of 15 activities were assessed by participants as to whether their caree was independent for each. The scale is a 3-point Likert scale where 0=Independent, 1=Some help required, and 2=Completely dependent. Examples of items are ‘Eating’, ‘Doing heavy housework and laundry’, ‘Doing yard work’, and ‘Handling long-term finances’.

Based on Chappell and Reid (2002), to create an overall functional dependency score, all 15 items were summed and divided by the total number of valid responses for each respondent (range 0-2). Higher scores
indicated less functional dependency of the caree on their caregiver. This scale has been found to be highly reliable (Cronbach’s coefficient alpha of .93) (Chappell & Reid, 2002). For the present study, the Cronbach’s alpha reliability for the Functional Dependency Scale was .94, indicating high internal consistency.

Informal hours of caregiving and formal service hours. Based on Chappell and Reid (2002), caregivers were asked two questions, one related to how many hours of formal services they receive per week, and the other was associated with how many hours they spend providing care per week. These questions were ‘During the past week how many hours have you spent providing care?’, and ‘How many hours would you currently receive formal services whether inside or outside the home’. Based on Chappell and Reid (2002), for each item, the log of the score was taken. Higher scores indicated that in the last week more informal hours of care had been provided and more time was spent using formal services, respectively.

Perceived social support. Perceived social Support was measured by the Perceived Social Support Scale (PSSS) (Blumenthal et al., 1987). This scale consists of 12 items and three subscales relating to social support from family, friends, and significant others. Statements were assessed by participants using a 7-point Likert scale where 0=Very strongly disagree and 6=Very strongly agree. Examples of statements are ‘There is a special
person who is around when I am in need’, and ‘My family really tries to help me’.

Based on Blumenthal et al. (1987), all item scores were summed to produce an overall perceived social support score ranging from 0-72. Higher scores indicated a higher level of perceived social support. This scale has been found to be highly reliable (Cronbach’s coefficient alpha of .88, .91, .87, and .85 for the total scale, significant other, family, and friends respectively) (Blumenthal et al., 1987). For the present study, the Cronbach’s alpha reliability for the total Perceived Social Support Scale was .94, indicating high internal consistency.

Frequency of breaks. The frequency of breaks from Caregiving was measured using the Frequency of Breaks from Caregiving Scale (Chappell & Reid, 2002). This scale consists of 20 items and measures the types of activities that caregivers receive a break for and the frequency of breaks.

The first component of each item consists of details of an activity. For example, ‘Participating in organised social activities such as clubs’ or ‘Having time alone or time to yourself’. This was assessed by participants on a dichotomous scale as to whether or not they received a break that way, 1=Yes and 0=No. The second element of each item referred to how frequently caregivers received a break for that activity. This was assessed by participants on a 9-point Likert Scale where 0=Never, 1= Few times a year, 2= Once a month, 3= 2-3 times a month, 4=Once per week, 5=Twice
per week, 6=3-4 times per week, 7=5-7 times per week, and 8=Twice a day or more.

Consistent with Chappell and Reid’s (2002) method, factor analysis using orthogonal, varimax rotation was conducted on this scale. Following factor analysis, Chappell and Reid (2002) found the scale to be highly reliable (Cronbach’s alpha coefficient of .71) (Chappell & Reid, 2002). For the present study, factor analysis produced one main factor (eigenvalue=5.50) including all items except for item 37 which was ‘Going to work or school or volunteering’. A reliability analysis revealed that item 37 was the least reliable item. Therefore, item 37 was removed from the scale. With the removal of item 37, the scale (19 items) was found to be highly reliable (Cronbach’s alpha coefficient of .84). The interpretation of the factor analysis and item removal was discussed and supported by the original author (N.L. Chappell, personal communications, July 14, 2006).

Based on Chappell and Reid (2002), an overall frequency of breaks score was obtained by summing the second component of each item (how frequently the caregiver received a break), excluding item 37 and then dividing the sum by the number of non-zero responses. The theoretical range for this scale was 0-8; higher scores indicated a higher frequency of breaks from caregiving.

**Self-esteem.** Caregiver self-esteem was measured using the Self-Esteem Scale (Rosenberg, 1965). Self-statements were assessed by participants on a 4-point Likert scale where 3=Strongly Disagree, 2=Disagree, 1=Agree,
and 0=Strongly Agree. Examples of items are ‘I feel I have a number of good qualities’, ‘On the whole I am satisfied with myself’, and ‘I certainly feel useless at times’.

Based on Rosenberg (1965), an overall score was the sum of all 10 items (items 3, 5, 8, 9, 10 were reverse scored). The theoretical range for this scale was 0-40. Typically lower scores indicated lower self-esteem, however, for the current study, the scoring was reversed to avoid any confusion in the interpretation of the results. Therefore, higher scores indicated higher self-esteem. This scale has been found to be highly reliable (Cronbach’s alpha coefficient of .86) (Chappell & Reid, 2002). For the present study, the Cronbach’s alpha reliability for the Self-Esteem Scale was .87, indicating high internal consistency.

**Quality of the caregiver-caree relationship.** The quality of the relationship between the caregiver and the caree was measured using the Relationship Assessment Scale (RAS) (Hendricks, 1988). Statements were assessed by participants as to how satisfied they were with their current relationship with the caree. The scale is a 5-point Likert scale with variable ranking scores. Examples of items are ‘How well does your partner meet your needs’, ‘How often do you wish that you had not gotten into this relationship’, and ‘How many problems are there in your relationship’.

Based on Hendricks (1988), an overall score was the sum of all seven items (items 4 and 7 were reversed scored). The theoretical range for this scale was 7-35; higher scores indicated greater relationship satisfaction.
This scale has been found to be highly reliable (Cronbach’s alpha coefficient of .86) (Hendricks, 1988). For the present study, the Cronbach’s alpha reliability for the Relationship Assessment Scale was .93, indicating high internal consistency.

**Burden.** Caregiver Burden was measured using the Caregiver Burden Inventory (CBI) (Novak & Guest, 1989). The CBI consists of 24 items and five subscales relating to specific dimensions of caregiver burden. These include time-dependence burden (i.e., ‘I don’t do as good a job at work as I used to’), developmental burden (i.e., ‘I feel that I am missing out on life’), physical burden (i.e., ‘My health has suffered’), social burden (i.e., ‘My social life has suffered’), and emotional burden (i.e., ‘I resent my care receiver’).

Statements were assessed by participants using a 5-point Likert scale where 0=Strongly disagree and 4= Strongly agree. Based on Novak and Guest (1989), an overall burden score was the sum of all 24 items. The theoretical range for this scale was 0-96; higher scores indicated greater caregiver burden. This scale has been found to be highly reliable (Cronbach’s coefficient alpha of .85, .85, .86, .73, and .77 for factors one to five respectively) (Novak & Guest, 1998). For the present study, the Cronbach’s alpha reliability for the total Caregiver Burden Inventory was .94, indicating high internal consistency.
Quality of life. Caregiver quality of life was measured using the Scale of Quality of Life of Care-givers (SQLC) (Glozman, Bicheva, & Fedorova, 1998). The SQLC measures three aspects of the quality of life of Parkinson’s disease caregivers. These include professional activity, social and leisure activities, and responsibilities to help the patient in everyday living. For each question the caregiver was required to answer on a dichotomous scale (i.e., Yes or No) and on a Likert scale with variable ranking scores for each item. Examples of items are ‘Do you continue to discuss family plans and problems with your ill relative’, ‘Did you change work because of your relative’s disease?’, and ‘Can your caree call for a physician by themselves?’.

Based on Glozman et al.’s (1998) method, in order to produce a single caregiver quality of life score, all 16 item scores were summed. Higher scores indicated higher perceived caregiver quality of life. Four degrees of caregiver distress can be determined: None=141-149, Mild=140-100, Moderate=99-86, and Severe=less than 85 points. The SQLC has demonstrated high internal consistency (Cronbach’s coefficient alpha of .80) (Martinez-Martin et al., 2005). For the present study, the Cronbach’s alpha reliability was .87, indicating high internal consistency.

Procedure

Approval for the use of the questionnaire was obtained from Swinburne University’s Ethics Committee on the 24th of April, 2006. Prior to the distribution of the questionnaire, approval was also obtained by Parkinson’s
Victoria. Participants were mailed the questionnaire with a covering letter explaining Parkinson’s Victoria’s support for the study and a postage paid addressed envelope for the return of the completed questionnaire. In addition, a small letter was included suggesting that if they were not the caregiver of a patient with Parkinson’s disease that they pass the questionnaire onto someone who is or return the questionnaire blank. The participants were also informed that their participation was voluntary and that the completion and return of the questionnaire would be regarded as informed consent.

The questionnaire was also posted on Swinburne University’s Opinio website. Links to this site were posted on the Villa Maria Disability Services, Parkinson’s Victoria, South Australia, and New South Wales websites and on a number of Parkinson’s newsgroups and forums on the Internet. The questionnaire was available online for a period of four months, from 9 May 2006 to 9 August 2006.
Results

Data was analysed using the Statistical Package for the Social Sciences (SPSS) version 14.0. Preliminary data screening was performed to ensure that there were no significant violations of the assumptions of sample size, normality and linearity of data, lack of multi-collinearity and multivariate outliers, and normally distributed residuals.

To examine the reliability of the estimates and standard errors, the ratio of sample size to the number of parameters to be tested was calculated. A ratio of approximately 1:4 was revealed. As suggested by Bentler (1995), the ratio may go as low as 1:5 if the variables are normally distributed. In addition, a sample size of about 200 is adequate for small to medium models (Boomsma, 1982). According to these statisticians, for the current analysis, the sample size and ratio may have been questionable. However, as suggested by Boomsma and Hoogland (2001), when the measurement instruments are strong in terms of reliability and validity (as they were in this study), this may compensate for small sample size and reduce non-convergence and improper solutions. In addition, SEM estimates are more robust than others against the effect of sample size. Specifically, Maximum Likelihood estimates have good statistical properties compared to other techniques (e.g., Generalized Least Squares, Asymptotically Distributions Free, etc.) and require a smaller sample size (Boomsma & Hoogland, 2001).

Preliminary screening also revealed a small number of missing values. Due to the fairly large sample size, any recognised treatment for missing values was believed to be appropriate (Tabachnick & Fidell, 2001).
preserve the mean of the data distribution for each variable, for each case where less than 30% of the data was missing for a particular scale, the missing value was replaced with the mean for that item (Tabachnick & Fidell, 2001). As indicated by Mardia’s coefficient and histograms, some variables were skewed, non-linear, and exhibited significant negative or positive kurtosis. However, given the nature of the sample, transformations were not applied (Tabachnick & Fidell, 2001). This may have resulted in an underestimation of the variance and an underestimation of relationships (Tabachnick & Fidell, 2001). Calculation of Mahalanobis distance revealed no multivariate outliers.

By computing the standardised residual values it was revealed that all residuals were normally distributed, indicating that no statistically significant discrepancy lies with the covariance between any variables (Byrne, 2001). Lastly, as found by Pearson’s correlation coefficients, there was no evidence of multi-collinearity.

Statistical analysis comparing caregivers with medical conditions and those without medical conditions indicated that there were significant differences in caregiver quality of life. In particular, those with medical conditions had significantly lower levels of quality of life than those without medical conditions, $t(132) = -2.91, p < .006$. While it acknowledge that these differences have been found, due to the small sample size, caregivers with and without medical conditions were collapsed for the purpose of this study. The possible impact of these significant findings in the combined results will be outlined in the discussion section.
Descriptive analysis

Preliminary analysis of participant responses was also used to examine the frequencies and descriptive statistics for all variables incorporated in the proposed model. Table 4 provides a summary of the means, standard deviations, and possible ranges for all variables including; caregiver stressors, informal hours of caregiving, protective factors, and caregiver burden and quality of life.

Table 4

Means, Standard Deviations, Sample Size, and Theoretical Range for Caregiver Stressors, Informal Hours of Caregiving, Protective Factors, and Caregiver Burden and Quality of Life.

<table>
<thead>
<tr>
<th>Variable name</th>
<th>M</th>
<th>SD</th>
<th>Possible range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caree cognitive impairment</td>
<td>5.62</td>
<td>4.32</td>
<td>0-14</td>
</tr>
<tr>
<td>Caree behavioural problems</td>
<td>9.10</td>
<td>6.45</td>
<td>0-40</td>
</tr>
<tr>
<td>Caree functional dependency</td>
<td>.93</td>
<td>.55</td>
<td>0-2</td>
</tr>
<tr>
<td>Informal hours of caregiving¹</td>
<td>1.61</td>
<td>.51</td>
<td></td>
</tr>
<tr>
<td>Perceived social support</td>
<td>45.54</td>
<td>15.80</td>
<td>0-72</td>
</tr>
<tr>
<td>Frequency of breaks</td>
<td>4.82</td>
<td>4.64</td>
<td>0-8</td>
</tr>
<tr>
<td>Formal service hours¹</td>
<td>.57</td>
<td>.38</td>
<td></td>
</tr>
<tr>
<td>Self-esteem</td>
<td>31.88</td>
<td>4.85</td>
<td>0-40</td>
</tr>
<tr>
<td>Quality of caregiver-caree relationship</td>
<td>26.28</td>
<td>7.27</td>
<td>7-35</td>
</tr>
<tr>
<td>Burden</td>
<td>40.04</td>
<td>18.09</td>
<td>0-96</td>
</tr>
<tr>
<td>Quality of life</td>
<td>85.84</td>
<td>20.44</td>
<td>0-149</td>
</tr>
</tbody>
</table>

*Note. N=136. ¹=Logged values reported.*
As can be seen in Table 4, participants reported relatively higher levels of caree functional dependency than caree cognitive impairment or behavioural problems. The means for caregiver quality of life (a score of 86 is considered moderate distress) and burden indicate that the present sample had moderate levels of quality of life and relatively low levels of burden. The log of informal hours of caregiving and formal service hours were also relatively low.

**Correlational Analysis**

To examine the correlations between all variables in the proposed model, Pearson’s correlation coefficients were computed. Table 5 shows the correlations between all caregiver stressors, informal hours of caregiving, protective factors, and caregiver burden and quality of life.
<table>
<thead>
<tr>
<th></th>
<th>Caree cognitive impairment</th>
<th>Caree behavioural problems</th>
<th>Caree functional dependency</th>
<th>Informal hours caregiving</th>
<th>Perceived social support</th>
<th>Frequency of breaks</th>
<th>Formal service hours</th>
<th>Self-esteem</th>
<th>Quality of caregiver-caree relationship</th>
<th>Burden</th>
<th>Quality of life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caree cognitive impairment</td>
<td>.49**</td>
<td>.25**</td>
<td>.13</td>
<td>-.22**</td>
<td>-.16</td>
<td>.21*</td>
<td>-.17*</td>
<td>-.22*</td>
<td>.37**</td>
<td>-.20*</td>
<td></td>
</tr>
<tr>
<td>Caree behavioural problems</td>
<td>.57**</td>
<td>.20*</td>
<td>-.16</td>
<td>-.25**</td>
<td>.23**</td>
<td>.26**</td>
<td>-.38**</td>
<td>.65**</td>
<td>-.51**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caree functional dependency</td>
<td>.21*</td>
<td>-.06</td>
<td>-.25**</td>
<td>.23**</td>
<td>-.11</td>
<td>-.31**</td>
<td>.57**</td>
<td>-.74**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Informal hours of caregiving</td>
<td>-.13</td>
<td>-.31**</td>
<td>-.13</td>
<td>.10</td>
<td>.09</td>
<td>.27**</td>
<td>-.35**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived social support</td>
<td></td>
<td>.30**</td>
<td>-.02</td>
<td>.33**</td>
<td>.15</td>
<td>-.36**</td>
<td>.09</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency of breaks</td>
<td></td>
<td></td>
<td>-.14</td>
<td>.10</td>
<td>.05</td>
<td>-.45**</td>
<td>.41**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Formal service hours</td>
<td></td>
<td></td>
<td></td>
<td>.01</td>
<td>-.01</td>
<td>.18*</td>
<td>-.14</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-esteem</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.18*</td>
<td>-.28**</td>
<td>.07</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of caregiver-caree relationship</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-.54**</td>
<td>.25**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Burden</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-.59**</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note. N=136. *p<.05, **p<.01, ***p<.001.*
As can be seen from Table 5, all correlations between observed variables were below .90, satisfying the test for multi-collinearity. Caregiver stressors and informal hours of caregiving were found to have a positive relationship with caregiver burden and a negative relationship with caregiver quality of life. This indicated that caregivers with greater informal hours of caregiving and who care for those with more functional dependency, behavioural problems, and cognitive impairment, reported experiencing higher levels of burden and lower levels of quality of life.

All caregiver stressor variables were also found to be positively related to formal service hours. In addition, formal service hours was positively associated with caregiver burden. This indicated that those with higher levels of caregiver burden tend to use more hours of formal service. However, there was no significant relationship between formal service hours and caregiver quality of life.

When examining the other protective factors, it was revealed that both perceived social support and caregiver self-esteem had weak negative relationships with caregiver burden but no significant relationship with caregiver quality of life. Other protective factors such as the frequency of breaks and the quality of caregiver-caree relationship also had significant negative relationships with caregiver burden, however these protective factors were also positively associated with caregiver quality of life. In addition, caregiver quality of life and burden had a moderate negative relationship, indicating that as caregiver quality of life increased, caregiver burden decreased.
Path Analysis

A path analysis was performed to assess the pattern of relationships between caregiver stressors, informal hours of caregiving, protective factors, and caregiver well-being (specifically burden and quality of life).

In view of the violation of the assumption of population normality for this medium sized sample and due to the relatively small ratio of sample size to the number of parameters tested, an extended version of Chappell and Reid’s (2002) model was assessed using Maximum Likelihood criterion, and incorporating the Bollen-Stine bootstrap and standardised estimates. Extending upon Chappell and Reid’s (2002) model and based upon previous research findings, the quality of the caregiver-caree relationship and caregiver quality of life were added to the proposed model. The output was then examined in consideration of Modification Indices.

The AMOS program provided Modification Indices as an indication of possible pathways between variables, the inclusion or removal of which may affect the overall fit of the model. In the analysis of the extended version of Chappell and Reid’s (2002) model, 22 additional paths suggested by the modification indices were incorporated to provide pathways. These were:

1. Caree behavioural problems <--- How far away the caree lives
2. Caree behavioural problems <--- Age
3. Caree functional dependency <--- How far away the caree lives
4. Informal hours of caregiving <--- Age
5. Informal hours of caregiving <--- Caree functional dependency
6. Informal hours of caregiving <--- Perceived social support
7. Perceived social support <--- Caree cognitive impairment
8. Frequency of breaks <--- How far away the caree lives
9. Frequency of breaks <--- Perceived social support
10. Frequency of breaks <--- Caree functional dependency
11. Frequency of breaks <--- Gender
12. Formal service hours <--- How far away the caree lives
13. Self-esteem <--- Informal hours of caregiving
14. Self-esteem <--- Caree behavioural problems
15. Self-esteem <--- Perceived social support
16. Quality of caregiver-caree relationship <--- How far away the caree lives
17. Quality of caregiver-caree relationship <--- Age
18. Quality of caregiver-caree relationship <--- Caree behavioural problems
19. Burden <--- How far away the caree lives
20. Burden <--- Caree functional dependency
21. Burden <--- Perceived social support
22. Quality of life <--- Age

All remaining suggested additional pathways were not incorporated in the model as they were not justifiable in view of the theoretical underpinnings of the model. Once these pathways were incorporated, this model was processed again using Maximum Likelihood criterion, incorporating the Bollen-Stine bootstrap, and standardised estimates. Significant standardised regression weights (betas) for the caregiver well-being model are shown in Table 6.
Table 6.

*Significant Standardised Regression Weights (Betas) for the Caregiver Well-being Model.*

<table>
<thead>
<tr>
<th>Path</th>
<th>Regression weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caree behavioural problems &lt;--- Functional dependency</td>
<td>.52 (*** )</td>
</tr>
<tr>
<td>Caree behavioural problems &lt;--- Cognitive impairment</td>
<td>.34 (*** )</td>
</tr>
<tr>
<td>Caree behavioural problems &lt;--- How far away the caree lives</td>
<td>-.14 (*)</td>
</tr>
<tr>
<td>Caree behavioural problems &lt;--- Age</td>
<td>-.19 (**)</td>
</tr>
<tr>
<td>Caree functional dependency &lt;--- Cognitive impairment</td>
<td>.26 (*** )</td>
</tr>
<tr>
<td>Caree functional dependency &lt;--- How far away the caree lives</td>
<td>.32 (*** )</td>
</tr>
<tr>
<td>Informal hours of caregiving &lt;--- Functional dependency</td>
<td>.27 (**)</td>
</tr>
<tr>
<td>Informal hours of caregiving &lt;--- How far away the caree lives</td>
<td>-.28 (*** )</td>
</tr>
<tr>
<td>Informal hours of caregiving &lt;--- Age</td>
<td>.23 (**)</td>
</tr>
<tr>
<td>Informal hours of caregiving &lt;--- Frequency of breaks</td>
<td>-.17 (*)</td>
</tr>
<tr>
<td>Perceived social support &lt;--- Caree cognitive impairment</td>
<td>-.16 (*)</td>
</tr>
<tr>
<td>Perceived social support &lt;--- Age</td>
<td>.37 (*** )</td>
</tr>
<tr>
<td>Perceived social support &lt;--- Gender</td>
<td>-.17 (*)</td>
</tr>
<tr>
<td>Perceived social support &lt;--- Informal hours of caregiving</td>
<td>-.19 (*)</td>
</tr>
<tr>
<td>Frequency of breaks &lt;--- Perceived social support</td>
<td>.30 (*** )</td>
</tr>
<tr>
<td>Frequency of breaks &lt;--- How far away the caree lives</td>
<td>.27 (*** )</td>
</tr>
<tr>
<td>Frequency of breaks &lt;--- Caree functional dependency</td>
<td>-.29 (*** )</td>
</tr>
<tr>
<td>Frequency of breaks &lt;--- Gender</td>
<td>.27 (*** )</td>
</tr>
<tr>
<td>Formal service hours &lt;--- Caree cognitive impairment</td>
<td>.22 (**)</td>
</tr>
<tr>
<td>Formal service hours &lt;--- How far away the caree lives</td>
<td>.25 (**)</td>
</tr>
<tr>
<td>Self-esteem &lt;--- Caree behavioural problems</td>
<td>-.25 (**)</td>
</tr>
<tr>
<td>Self-esteem &lt;--- Perceived social support</td>
<td>.32 (*** )</td>
</tr>
<tr>
<td>Self-esteem &lt;--- Informal hours of caregiving</td>
<td>.19 (*)</td>
</tr>
<tr>
<td>Quality of caregiver-caree relationship &lt;--- How far away the caree lives</td>
<td>-.17 (*)</td>
</tr>
</tbody>
</table>
Table 6. Significant Standardised Regression Weights (Betas) for the Caregiver Well-being Model (continued).

<table>
<thead>
<tr>
<th>Path</th>
<th>Regression weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of caregiver-caree relationship &lt;--- Age</td>
<td>.21 (**)</td>
</tr>
<tr>
<td>Quality of caregiver-caree relationship &lt;--- Caree behavioural problems</td>
<td>-.33 (***)</td>
</tr>
<tr>
<td>Burden &lt;--- Caree functional dependency</td>
<td>.29 (***))</td>
</tr>
<tr>
<td>Burden &lt;--- Caree behavioural problems</td>
<td>.29 (***))</td>
</tr>
<tr>
<td>Burden &lt;--- Perceived social support</td>
<td>-.20 (***)</td>
</tr>
<tr>
<td>Burden &lt;--- Frequency of breaks</td>
<td>-.21 (***))</td>
</tr>
<tr>
<td>Burden &lt;--- Quality of caregiver-caree relationship</td>
<td>-.34 (***))</td>
</tr>
<tr>
<td>Burden &lt;--- How far away the caree lives</td>
<td>-.14 (*)</td>
</tr>
<tr>
<td>Quality of life &lt;--- Caree Functional dependency</td>
<td>-.57 (***))</td>
</tr>
<tr>
<td>Quality of life &lt;--- Age</td>
<td>-.19 (***)</td>
</tr>
<tr>
<td>Quality of life &lt;--- Frequency of breaks</td>
<td>.16 (**))</td>
</tr>
<tr>
<td>Quality of life &lt;--- Burden</td>
<td>-.24 (***))</td>
</tr>
</tbody>
</table>

Note. N=136. *p<.05, **p<.01, ***p<.001.

As can be seen from Table 6, a number of the control variables (e.g., age, gender, and how far away the caree lives) were significantly associated with the independent and dependent variables. Caregiver age was significantly positively associated with informal hours of caregiving, the quality of the caregiver-caree relationship, and perceived social support. In addition, this control variable was negatively related to caree behavioural problems, and caregiver quality of life.

Furthermore, how far away the caregiver lived was significantly positively associated with caree functional dependency, frequency of breaks, and formal service hours. This variable was also negatively related to caree behavioural problems, informal hours of caregiving, the
quality of the caregiver-caree relationship, and caregiver burden. Lastly, caregiver gender was significantly positively associated with the frequency of breaks and negatively related to perceived social support.

Of the primary stressors, only caree behavioural problems and functional dependency were significantly positively associated with caregiver burden. That is, as caree behavioural problems and functional dependency increased, so to did caregiver burden. However, caree functional dependency was also negatively related to caregiver quality of life. Lower caree functional dependency scores led to higher quality of life scores.

A number of protective factors also had significant direct effects on caregiver quality of life and burden. The quality of the caregiver-caree relationship, perceived social support, and the frequency of breaks were negatively associated with caregiver burden. Higher perceived social support, frequency of breaks, and caregiver-caree relationship quality, led to lower burden. The frequency of breaks was also directly associated with caregiver quality of life. Specifically, a higher frequency of breaks led to higher caregiver quality of life. Based on the significant regression weights, a path model of caregiver burden and quality of life was constructed (See Figure 4).
Figure 4. Path model of caregiver burden and quality of life.

Note. Only pathways with significant regression weights are shown. $N=136$. *$p<.05$, **$p<.01$, ***$p<.001$. 

-19**
As shown in Figure 6, a number of indirect relationships were found. Perceived social support and formal service hours were directly influenced by caree cognitive impairment. However, neither variable acted as a mediator of caregiver quality of life. Though, perceived social support affected the relationship between caree cognitive impairment and caregiver burden. An increase in caree cognitive impairment was associated with a decrease in perceived social support, which led to an increase in caregiver burden. Other protective factors such as the quality of the caregiver-caree relationship and the frequency of breaks also affected the relationships between caregiver stressors and caregiver well-being.

The quality of the caregiver-caree relationship was found to mediate the relationship between caregiver burden and caree behavioural problems. As the number of caree behavioural problems decreased, the quality of the caregiver-caree relationship increased, which led to a decrease in caregiver burden. The frequency of breaks also acted as a mediator. A decrease in caree functional dependency was associated with an increase in the frequency of breaks, and led to a decrease in caregiver burden and an increase in caregiver quality of life.

Control variables such as how far away the caregiver lived also formed mediating relationships. An increase in the functional dependency of the caree, was positively associated with how far away the caregiver lives, and led to a decrease in caregiver burden. How far away the caregiver lived also acted as a mediator of the relationship between caree
behavioural problems and caregiver burden. An increase in caree
behavioural problems was associated with a decrease in how far away the
caregiver lived, which led to an increase in caregiver burden.

Lastly, how far away the caregiver lived mediated the relationship
between a number of protective factors and caregiver burden. The further
away the caregiver lived, the lower the quality of the caregiver-caree
relationship, which led to an increase in caregiver burden. In addition, the
further away the caregiver lived, the higher the frequency of breaks,
which led to lower caregiver burden and higher quality of life.

Assessing the fit of the model

The fit of the model was assessed using fit indices, the selection of
which was influenced by the estimation method used, sample size, the
complexity of the model and the degree to which the assumption of
multivariate normality was violated. Overall the model was found to be a
good fit of the data. This was assessed using the Chi-squared statistic, the
Normed Chi-squared statistic, and the Root Mean-Squared Error of
Approximation (RMSEA). The incremental fit indices used for this
analysis were Comparative Fit Index (CFI), Incremental Fit Index (IFI),
and the Tucker-Lewis Index (TLI).

For the current model, the value of the Chi-squared statistic was 67.87,
df= 55, p>.05. This suggested that the model was a good fit of the data.
However, as suggested by Byrne (2001), the Chi-squared statistic ($\chi^2$) is
highly sensitive to sample size and thus should not be used as the only
indicator of goodness of fit between the model and the data. Therefore, the Normed Chi-squared statistic was also calculated. The Normed Chi-squared statistic was within the accepted range of 1-3, ($\chi^2/df = 1.23$), indicating a good fitting model.

Byrne (2001) suggested that the evaluation of the model should also be based on alternative realistic indices of fit. For the current study, the goodness of fit indices suggested that the model was a good fit of the data as they were all well above .90 (CFI=.98, IFI=.98, TLI=.96) and the RMSEA was .04. The parsimony goodness of fit index (PGFI) was .50, which is deemed acceptable in view of the non-significant $\chi^2$ statistic and the strength of the fit indices (Byrne, 2001).

Testing the null hypothesis that the model is correct, the Bollen-Stine bootstrap was not significant ($p = .36$), which demonstrated that the model is appropriate. The Square Multiple Correlation (SMC) indicated that 64.2% and 68.9% of the variance in Quality of life and Burden, respectively were explained by this model.
Discussion

Using an extended version of Chappell and Reid’s (2002) stress-appraisal model, this study sought to further investigate the relationships between caregiver stressors, informal hours of caregiving, protective factors, and caregiver well-being (specifically quality of life and burden). It also aimed to improve and extend upon Chappell and Reid’s (2002) model by more extensively investigating the well-being of caregivers as well as by investigating the protective role of the quality of the caregiver-caree relationship. Also, this study aimed to take the limitations of previous research into account by using more specific caregiving measures and by investigating a population of Parkinson’s disease caregivers.

Empirical evidence in support of this extended version of Chappell and Reid’s (2002) model of caregiver well-being has been presented in this study. The model was a good fit of the data and the variables were shown to be effective predictors of caregiver quality of life and burden. The findings as they pertain to each hypothesis will now be discussed.

Review of findings in relation to hypotheses

Primary stressor and caregiver well-being. Results from the current analysis partially supported the hypotheses that increased caregiver stressors (i.e., caree cognitive impairment, behavioural problems, and functional dependency) as well as increased informal hours of caregiving would be adversely related to caregiver quality of life and burden.

Contrary to expectations and previous research (Aarsland et al., 1999; Thommessen et al., 2002; Yates et al., 1999), caree cognitive impairment
was not associated with caregiver burden or quality of life. However, an increase in caree behavioural problems and functional dependency was found to have an adverse impact on caregiver burden. Furthermore, an increase in caree functional dependency adversely impacted caregiver quality of life. These findings replicate substantial earlier work (Aarsland et al., 1999; Goode et al., 1998; Lawrence et al., 1998; M.P Lawton et al., 1991; Martinez-Martin et al., 2005; B. Miller et al., 2001; Thommessen et al., 2002; Yates et al., 1999).

These results also partially support Chappell and Reid (2002) upon whose research the current study was modelled. Chappell and Reid (2002) found that caregiver burden was not influenced by caree cognitive impairment or functional dependency but was adversely related to caree behavioural problems.

The present study aimed to improve on Chappell and Reid’s (2002) research by using a population of Parkinson’s disease caregivers, rather than a non-specific population of caregivers. Therefore the results may indicate that an increase in caree behavioural problems is adversely associated with caregiver burden for a variety of caregiver populations. In contrast, the negative relationship between caree functional dependency and caregiver well-being may be specific to caring for Parkinson’s disease patients or those with other similar health problems. As indicated by the lower scores on caree cognitive impairment and behavioural problems but relatively higher scores on caree functional impairment, this may reflect the pathology of Parkinson’s disease (i.e., those with Parkinson’s disease may
suffer more functional impairment than cognitive or behavioural impairment).

This explanation may be plausible given the consistency between results from the current study and results from a number of independent researchers (Aarsland et al., 1999; Martinez-Martin et al., 2005; Thommessen et al., 2002) who also used a population of Parkinson’s disease caregivers. Furthermore, a number of researchers (B. Miller et al., 2001; Thommessen et al., 2002) have found that different caregiving factors are related to different populations of caregivers. For example, Thommessen et al. (2002) found that caree functional dependency was negatively related to caregiver burden in caregivers for those with Parkinson’s disease and Dementia but this relationship did not exist for caregivers of Stroke patients.

It is also possible that previous researchers (Chappell & Reid, 2002; Lawrence et al., 1998) found no relationship between caree functional dependency and caregiver burden as they used unidimensional measures of caregiver burden. These measures may not have assessed the specific areas of caregiver burden that are related to caree functional dependency. The current study aimed to improve on Chappell and Reid’s (2002) research by using a multidimensional measure of caregiver burden. Therefore, it is possible that for the present study, the level of caree functional dependency was related to the additional aspects of caregiver burden that were assessed.

This is further supported by the findings from a number of independent researchers (Aarsland et al., 1999; Martinez-Martin et al., 2005; Thommessen et al., 2002) who used a wide range of multidimensional
measures of caregiver burden and found that an increase in caree functional
dependency is adversely related to caregiver stress, quality of life, and
burden. However, these researchers used a population of Parkinson’s
disease caregivers. Therefore, it is difficult to determine if this relationship
is due to the use of a multidimensional measure or due to the fact that the
relationship between caree functional dependency and caregiver well-being
is specific to caring for a population of Parkinson’s disease patients or those
with other similar health conditions. Alternatively, the relationship may be
a result of the combination of both factors.

The present study also found that caregivers with medical conditions had
a lower quality of life than those without medical conditions. A large
proportion of caregivers in the current study had medical conditions
(42.6%). However, for the purpose of the study caregivers with and
without medical conditions were collapsed. Consequently, the findings that
caree functional dependency and behavioural problems are adversely
related to caregiver well-being may be partly due to the fact that these
caregiver stressors are difficult to manage for caregivers with their own
physical (e.g., arthritis, fatigue, etc.) and psychological (e.g., a lack of
patience and motivation) symptoms. In contrast, caree cognitive
impairment may not be as physically and psychologically challenging for
caregivers with their own medical conditions.

Informal hours of caregiving and caregiver well-being. Contrary to
previous research (Chappell & Reid, 2002; Hirst, 2005; M.P Lawton et al.,
1991; Yates et al., 1999) and in contrast to expectations, informal hours of
caregiving was not associated with caregiver burden. However, an increase in the informal hours of caregiving resulted in an increase in caregiver self-esteem. This association replicates extensive prior research (Davey, 2005; Rees et al., 2001; Szmukler et al., 1998), suggesting that caregiving can also be a satisfying positive experience.

The number of hours of informal caregiving was also associated with caree functional dependency. However in contrast to previous research (Chappell & Reid, 2002; Yates et al., 1999), caree cognitive impairment and behavioural problems were not directly or indirectly related to informal hours of caregiving. This implies that caree cognitive impairment and behavioural problems are less critical to the determination of the number of hours that Parkinson’s disease caregivers spend caregiving.

These findings may reflect the pathology of Parkinson’s disease (i.e., Parkinson’s disease sufferers tend to have higher levels of functional impairment than behavioural or cognitive impairment). This was supported by the relatively low scores on caree cognitive impairment and behavioural problems but higher scores on caree functional dependency.

Another explanation is that Parkinson’s disease is a progressive disease, and as the disease advances patients become increasingly physically disabled and dependent on their caregiver (Brod et al., 1998). Therefore, it makes sense that as caree functional dependency increases, more hours of caregiving are required. In contrast, caree cognitive impairment and behavioural problems are less likely to impact a caree’s ability to independently perform their daily activities. Therefore increases in these stressors are unlikely to influence the number of hours of caregiving.
Protective factors of caregiver well-being. The hypotheses that perceived social support, frequency of breaks, formal service hours, self-esteem, and the quality of caregiver-caree relationship would act as protective factors ameliorating the adverse effects of Parkinson’s disease on perceived caregiver quality of life and burden were partially supported. Three of the five protective factors; the frequency of breaks, the quality of the caregiver-caree relationship, and perceived social support directly influenced the effects of caregiver stressors on caregiver well-being.

Consistent with previous findings by Chappell and Reid (2002), an increase in the frequency of breaks ameliorated the adverse effects of Parkinson’s disease on caregiver burden and quality of life. These results suggest that increasing the frequency of breaks may be an important way to alleviate the adverse impact of caregiving on a caregiver’s well-being. However, in contrast to previous research (Chappell & Reid, 2002), as caree functional dependency increased, the frequency of breaks decreased and this adversely impacted caregiver well-being. Therefore, caregiver breaks may be especially important when caring for those with higher levels of functional dependency, as found in Parkinson’s disease populations.

The number of hours of informal caregiving also influenced the frequency that a caregiver received a break. In contrast to Chappell and Reid (2002), who found that an increase in the informal hours of caregiving lead to an increase in the frequency of breaks, the current study found that Parkinson’s disease caregivers who spend the most amount of time caregiving receive breaks less often.
One explanation for this finding is that, in contrast to Chappell and Reid’s (2002) study where only 37% of caregivers were married to their caree, the majority of participants in the current study were married to their caree (81.6%). This suggests that contrary to the current study, the majority of the caregivers in Chappell and Reid’s study were paid caregivers and therefore the more they worked, the more breaks they were entitled to receive.

The present study also found that caregivers who had lower social support and who live with their caree, receive breaks less often. These results make sense given that as the number of hours of caregiving increases, there may be less time to receive breaks and participate in social activities. Additional feedback provided by the participants, also supports these findings as caregivers commonly reported that they had less time for their own interests and that they desired more time for themselves.

Complementary to a number of researchers (Beeson et al., 2000; Chee & Mancini, 2002; Fried et al., 2005; Heru et al., 2004; Scharlach, 1987; Williamson & Shulz, 1990; Yates et al., 1999) the quality of the caregiver-caree relationship was also directly related to caregiver burden. The findings also replicate substantial earlier work indicating that having a higher caregiver-caree relationship quality is especially important in reducing caregiver burden for caregivers of those with more behavioural problems (Yates et al., 1999; Lawrence et al., 1998).

Several explanations are possible for this finding. One is that an increase in caree behavioural problems (e.g., inability to resist impulses and resistance to change) may lead to a number of resentful feelings in the
caregiver (e.g., frustration, decreased patience, etc.). Consequently, this may result in a reduction in caregiver-caree relationship quality and an increase in caregiver burden.

Another possibility is that, closer caregiver-caree relationships make it easier for caregivers to control caree behavioural problems. This may lead to lower levels of caregiver burden. In contrast, caree cognitive impairment and functional dependency may be more difficult symptoms for caregivers to manage even if the quality of the caregiver-caree relationship is very high.

In terms of perceived social support, it was found that an increase in this protective factor was associated with a decrease in caregiver burden. This replicates earlier research (Chappell & Reid, 2002; Goode et al., 1998; Haley et al., 1987; E. Miller et al., 1996; Pagel & Becker, 1987). Additional feedback provided by the participants also supports these findings, as many caregivers reported that they desired more social support. However, in contrast to previous research (Chappell, & Reid, 2002; Yates et al., 1999), when caree cognitive impairment increased, perceived social support acted as a protective factor ameliorating the adverse effects of Parkinson’s disease on caregiver burden.

One explanation for this finding is that caregivers who care for those with lower levels of cognitive impairment tend to see their social support as more adequate than those who care for caree’s with higher levels of cognitive impairment. Therefore, the degree of caree cognitive impairment may contribute towards the perceived level of social support of caregivers. For example, caregivers of those who have higher cognitive impairment
may regard themselves as requiring more assistance and social support and that they should not handle things on their own.

Alternatively, increases in caree cognitive impairment (e.g., failing to remember names and faces, blaming others for problems, poor interpersonal problem solving, etc.) may lead to a decrease in the caree’s ability and desire to participate in social activities. It is well known that married couples tend to participate in social activities together and that they commonly share a network of mutual friends (Milardo, 1982). Therefore, as the majority of caregivers in the current study were married to their caree (81.6%), this may adversely impact the frequency of social support for the caregiver.

Although the majority of protective factors were related to caregiver well-being, both formal service use and caregiver self-esteem were not. An increase in formal service use was associated with an increase in caree cognitive impairment but this protective factor was not related to caregiver well-being. This finding supports earlier work indicating that formal service use may be part of the caregiving lifestyle and contribute towards maintaining caregiver well-being when caree cognitive impairment increases (Chappell & Reid, 2002; Yates et al., 1999). Given that these findings were consistent with a number of researchers (Chappell & Reid, 2002; Tennstedt et al., 1993; Yates et al., 1999), who used non-specific populations of caregivers, formal service use may maintain caregiver well-being when caree cognitive impairment increases in those with a variety of health conditions.

However, in contrast to previous researchers (Chappell & Reid, 2002; Tennstedt et al., 1993; Yates et al., 1999), the current study found that caree
functional dependency was not associated with formal service use. These results suggest that unlike caring for the elderly population, the level of caree functional dependency may not impact the amount of formal services use for Parkinson’s disease caregivers.

This may be due to the fact that unlike the elderly population, those with Parkinson’s disease are usually prescribed medication that is effective for the physical symptoms for approximately ten years (Marjama-Lyons & William, 2001). Consequently, caregivers may have time to adjust, make appropriate changes, and learn how to plan, and rely on themselves rather than using other services. This was supported by the low number of formal service hours that was reported by Parkinson’s disease caregivers. Other explanations are that there is currently a lack of services for Parkinson’s disease caregivers. Alternatively, caregivers may be unaware of their available resources.

Lastly, caregiver self-esteem did not act as a protective factor against the adverse impact of caregiving. This finding is inconsistent with substantial earlier work (Chappell & Reid, 2002; Pagel & Becker, 1987; Talkington-Boyer & Smith, 1994) using a population of either caregivers of the elderly or Alzheimers disease patients. The present study found that caregiver self-esteem was most affected by caree behavioural problems, perceived social support, and informal hours of caregiving. These results suggest that Parkinson’s disease caregivers of those with more behavioural problems tend to have a lower self-esteem and this may lead to a lower level of perceived social support and therefore a higher level of burden.
Implications of findings

Results with regard to the relationships between the caregiver stressors and caregiver well-being suggest that increases in caree behavioural problems may be adversely related to caregiver well-being for caregivers of those with a variety of illnesses. However, it is possible that caree functional dependency is a specific caregiver stressor related to caregiver well-being when caring for a Parkinson’s disease patient or those with other similar health conditions. If this is the case, there is great need for further research on these caregiver stressors and the development of appropriate interventions that aim to slow the progression of the disease both biophysically or through the use of effective psychosocial interventions.

Although a great deal of research has been conducted on the disease process and finding a cure for Parkinson’s disease, there has been little success in this area (Carter et al., 1998; Marjama-Lyons & William, 2001). Therefore, it is unlikely that a successful biophysical intervention will be found in the near future. Consequently, other interventions may be more appropriate in the short-term. For example, a program that focuses on providing caregivers with advice about understanding the problems associated with Parkinson’s disease and how to improve communication with their caree. This may assist by enhancing a caregiver’s ability to deal with the issues involved in caregiving and therefore improve their well-being.

However, a decrease in caree functional dependency was found to be associated with less informal hours of caregiving and this adversely impacted caregiver self-esteem. Therefore, if future biophysical
interventions are successful in slowing the progression of the disease, caregiver well-being may be enhanced but specific interventions that focus on enhancing caregiver self-esteem may be essential.

The current study also found that perceived social support, the quality of the caregiver-caree relationship, and the frequency of breaks acted as protective factors against the adverse effects of caring for a Parkinson’s disease patient. These results suggest that future support enhancing programs such as caregiver support and social groups should be extended to accommodate for Parkinson’s disease caregivers. Interventions could also be aimed to better equip caregivers to deal with the stressful issues associated with caring. Those who feel more able to deal with the issues of caregiving may be less inclined to withdraw their own social support.

However, an increase in caree cognitive impairment was found to be associated with lower levels of perceived social support. Therefore, these programs may be especially important for caregivers of those with higher levels of cognitive impairment. As suggested by the results, improving the perceived social support of caregivers may also have a beneficial effect on caregiver self-esteem and burden.

As a way to further increase caregiver well-being, interventions could focus on increasing the frequency that caregivers receive breaks. However, as suggested by the results, this could be difficult as the higher the caree functional dependency, the more informal hours of caregiving, and the lower the frequency of breaks. Therefore, for caree’s with higher functional dependency, multiple caregivers may be required. By implementing several caregivers, each caregiver could spend less hours
caregiving, and as a result they may have more time for breaks, leading to an increase in their perceived social support, and well-being. However, the results suggest that a decrease in the hours of caregiving negatively impacts caregiver self-esteem. Therefore specific interventions that focus on enhancing caregiver self-esteem may also be necessary.

The quality of the caregiver-caree relationship is also another potential intervention focus. Specific interventions such as support and social groups that involve caregivers and their carees could focus on improving the quality of the caregiver-caree relationship. Alternatively, programs that provide both the caree and the caregiver with advice about how to communicate better with each other and how to better understand the problems associated with the disease may be beneficial.

According to Lyons et al (2004), the interpretation of “the masked face” is one of the most common problems when communicating with a Parkinson’s disease sufferer. Therefore, programs could also focus on teaching caregivers ways to more accurately interpret and understand the meaning of caree facial expressions.

The current study found that an increase in caree behavioural problems was associated with a lower caregiver-caree relationship quality. Therefore, these programs may be especially important for caregivers of those with higher levels of behavioural problems. However, the most appropriate time for intervention may need to be explored. For example, a change in the quality of the relationship may occur when the caree is first diagnosed or when they are so severe that they are placed in a nursing
home or a hospital. Therefore, an intervention program may be most appropriate during these times.

Lastly, interventions that focus on enhancing caregiver self-esteem may also be important. Programs could assist caregivers in identifying the positive aspects about their current situation and their future. Alternatively, caregivers could undertake psychological treatment to enhance their self-esteem. The current study found that an increase in caree behavioural problems was associated with a decrease in caregiver self-esteem. Therefore, these programs may be especially important for caregivers of those with higher levels of behavioral problems. If interventions are successful in enhancing caregiver self-esteem, this may also lead to an increase in perceived social support.

The implications of this research spread beyond the realm of just Parkinson’s disease. As mentioned earlier, the results concurred with similar findings on the benefits of social support, frequency of breaks, and caregiver-caree relationship quality on a population of caregivers for the elderly, and for those with Alzheimer’s disease and other types of Dementia. However, it has previously been found that diverse relationships exist between caregiver stressors, appraisal, protective factors, and caregiver well-being for different disorders. Therefore, research into this area may benefit by looking at the relative influence of these factors for specific populations of caregivers.
Limitations of the research

There were a number of limitations in the present study that require consideration and might guide future research. As the sample comprised Parkinson’s disease caregivers, their responses may have been influenced by several factors. Firstly, the daily and hourly fluctuation in caree symptoms may have made it difficult for caregivers to accurately estimate the caree’s level of impairment. Caregivers who completed the questionnaire during their caree’s “on” period may have had different responses than if they completed it during an “off” period. No controls were put in place to exclude the confounding nature of fluctuating symptoms.

Further complicating the difficulty in estimating caree characteristics was the fact that the majority of carees (57.4%) had serious medical conditions other than Parkinson’s disease. It is likely that at times it was hard to distinguish between caree cognitive, behavioural, and functional symptoms due to Parkinson’s disease and those that resulted from another medical condition. Other caree medical conditions may have acted as a confounding variable.

A number of caregiver factors may have also influenced the results. As the average age of participants was 64.59 years old, complications related to ageing (e.g., poor eye sight, fatigue, etc.) may have made completing the questionnaire difficult. In addition, 42.6% of the caregivers had a medical condition themselves. This may have further complicated their ability to complete the questionnaire.

In addition, as more males are affected by Parkinson’s disease than females (Wooten et al., 2004), in general there are more female spousal
caregivers than male. The majority of caregivers in the current study were married to their caree (81.6%). Therefore, there were more female participants than male. However, this may have also been due to other factors such as the possibility that females are more likely to return questionnaires than males (Hill, Rubin, Peplau, & Willard, 1979). Although the current study found that there were no differences between males and females in their level of caregiver well-being, caregiver stressors, appraisal, and the majority of protective factors, a relatively small population of males was used. Therefore, they may not have been accurately represented.

Another factor that was not accounted for was the differences between early and late onset Parkinson’s. Although there is no set pattern to the symptoms and progression of Parkinson’s disease, those with early onset Parkinson’s disease have been found to have higher levels of depression than those with late onset Parkinson’s disease (Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2003; S.E. Starkstein, Berthier, Bolduc, Prezios, & Robinson, 1989). Furthermore, according to Fernandez, Tabamo, David, & Friedman (2001), an increase in caree depression is associated with an increase in caregiver depression. Therefore, it is likely that caregivers of those with early onset Parkinson’s disease would have lower baseline levels of well-being than caregivers of those with late onset Parkinson’s disease. As this study aimed to represent the whole range of Parkinson’s disease, the reliability may have been reduced.

There are also several other variables that were not controlled in this study that may influence the well-being of Parkinson’s disease caregivers. These include cultural factors, the economic situation, and other sources of
caregiver stress. Cultural factors may affect how the caregiving relationship is viewed. For example, caregivers from cultures that emphasise the importance of partners or relatives to care for their elders may report a lower level of burden and higher level of quality of life. The economic situation may also influence caregiver well-being. For example, caregivers who are less affluent may have reduced access to formal services and social support. There are also other sources of stress that may adversely impact caregiver well-being (e.g., negative interactions with other family members). Consequently, a lower level of caregiver quality of life may also be due to stressors that are unrelated to caregiving.

The method of recruitment of this sample was also problematic. All participants were recruited through Parkinson’s Victoria or related websites. Therefore caregivers with very high burden scores and informal hours of caregiving may not have had time to complete the questionnaire and send it back. These limitations were supported by the relatively low scores on caregiver burden and informal hours of caregiving. Furthermore, as caregivers were recruited through Parkinson’s Victoria or related websites, the participants had already sought additional sources of social support. If participants were recruited by other means, the average level of perceived social support, self-esteem, and well-being may have been lower.

Directions for further research

Future research is required to replicate the current study using a larger sample size and controlling for the limitations outlined, such as the gender ratio, other caree medical conditions, cultural, and economic factors, etc.
The reliability of the data could be improved in several ways. Firstly, a larger, more independent sample size with an equal ratio of males to females could be obtained by using a wider range of recruitment methods. For example, notices could be placed at caregiver support and social groups, in doctors’ surgeries and neurologists’ consulting rooms, more widely online, and an advertisement could be placed in newspapers or magazines that may be of interest to an older population. In addition, the questionnaire could be placed online for a longer period of time and more questionnaires could be mailed out to members of Parkinson’s Victoria and to members of other Parkinson’s disease associations.

Changing the method of data collection may also contribute towards an improvement in the reliability of the data. Responses could be collected by interview rather than self-report. This would eliminate the possibility of others influencing participant responses. In addition, other confounding variables that may be involved in estimating the caree’s level of impairment may be diminished. For example, caree impairment could be assessed at the interview rather than relying on the caregiver to estimate these factors. If possible, the assessment could be made by medical specialists (e.g., General Practitioners). Alternatively, additional research could be conducted on the measurement of variables specifically for a population of Parkinson’s disease caregivers. For example, specific caree cognitive impairment measures could focus on aspects that are relevant only to those with Parkinson’s disease.

The results of this study suggest that there are also other areas of Parkinson’s disease research that require particular attention. There was
evidence that caree functional dependency is a unique caregiver stressor specific to caring for those with Parkinson’s disease or other similar health conditions. In addition, the results suggest that caree functional dependency may be related to specific aspects of caregiver burden. Therefore, future studies may need to compare the relationship between caree functional dependency and caregiver well-being in populations of caregivers of those with Parkinson’s disease, other similar health conditions, and unrelated health conditions. In addition, further research is required on the separate domains of caregiver burden and how these relate to caregiver stressors, appraisal, and protective factors.

Future comparative studies could also investigate the nature of the relationships for late onset Parkinson’s disease and early onset Parkinson’s disease. In addition, in order to aid the effectiveness of interventions, the quality of the caregiver-caree relationship could be investigated at different stages of caregiving, for example, when first diagnosed, or when the caree is placed in a nursing home. Lastly, the well-being of caregivers with medical conditions and those without medical conditions could be more extensively explored and this factor could be incorporated into the model.

Summary and conclusions

In summary, the present study has added to the understanding of caregiver stressors, appraisals, and protective factors of caregiver well-being in a Parkinson’s disease population. Extending upon Chappell and Reid’s (2002) model, by using more extensive measures of caregiver well-being (i.e., QOL and burden), this study found that caree functional
dependency was negatively related to caregiver quality of life and that the frequency of breaks acted as a protective factor of caregiver quality of life. Further extending Chappell and Reid’s (2002) model, the quality of the caregiver-caree relationship was found to ameliorate the adverse effects of Parkinson’s disease on caregiver burden.

In accordance with the hypotheses, this research also found that increases in caree functional dependency and behavioural problems adversely impacted caregiver burden. Lastly, the results found that the frequency of breaks and perceived social support acted as protective factors of caregiver burden.

This research provides an important contribution to a growing field of research investigating stressors, appraisals, and protective factors that impact caregiver well-being. This study formed the basis for future comparative, longitudinal, and qualitative investigations into a model that represents the influence of stressors, appraisals, and protective factors on the well-being of Parkinson’s disease caregivers and caregivers of those with other similar illnesses. If extended prospectively, these results have implications for improving caregiver well-being and therefore the quality of care that Parkinson’s disease sufferers receive. This may also lead to better health outcomes for sufferers in terms of morbidity, mortality, and quality of life.
References


Are men at greater risk for Parkinson’s disease than women?


Appendix A:
Copy of Questionnaire
Caregivers of Parkinson’s disease patients

What it’s all about:

The aim of this project is to explore the influence of stressors and mediators on the quality of life and burden of caregivers. It is known that providing care to a patient with a chronic and debilitating disease can have extensive effects, not only on the caregivers physical health but also on their psychological health. In order to support caregivers in their role, it is necessary to understand the extent of caregiver-burden and factors associated with caregiver-burden and quality of life. Identifying these aspects can help to improve the lives of the carers and the quality of care for the care recipients.

What we are asking you to do:

Participation is voluntary and if you wish to take part, we are asking you to complete the attached questionnaire. The questions are about you, your experience of care-giving and possible mediators and stressors of your quality of life and burden as a result of caregiving. Please return the completed questionnaire in the pre-paid addressed envelope provided. Return of the completed questionnaire will be taken as your informed consent to participate.

The questionnaire should take about 30 minutes to complete. Please feel free to take a short break if necessary. If you are not able to complete the last five longer questions, the rest of the questionnaire is still extremely valuable without this part.

Confidentiality:

All responses are strictly confidential and material received will only be viewed by the researchers and then stored securely at Swinburne University. Your response to this study is completely anonymous and confidential. The data may be presented at conferences, in journal publications or used for class exercises but all identifying data will have been removed.
Concerns and Complaints:

If you have any concerns about the conduct of this research project, you can contact:

Research Ethics Officer,
Office of Research and Graduate Studies (H68)
Swinburne University of Technology
P O Box 218, Hawthorn
VIC 3122 Phone: (03) 9214 5218

If you have any questions about the project please contact:

Dr Simon Knowles Supervisor Phone: (03) 9214 8206
Email: sknowles@swin.edu.au

Dr Susan Moore Associate Supervisor Phone: (03) 9214 5694
Email: smoore@swin.edu.au

If completion of this questionnaire leads to feelings of distress or raises issues you would like to discuss with a counsellor, please contact:

Swinburne Psychology Clinic Phone: (03) 9214 8653 OR
Lifeline Phone: 13 11 14 (24-hour)

If you have any concerns about this project which the researcher was unable to satisfy please contact:

Head, School of Life and Social Sciences
Swinburne University of Technology
PO Box 218, Hawthorn
VIC 3122 Phone: (03) 9214 5017

Complaints about the way you were treated during this study may be directed to:

Chair, Human Research Ethics Committee (SBS)
Swinburne University of Technology
PO Box 218, Hawthorn
VIC 3122 Phone: (03) 9214 5223
Background information about you

This information is required so that we can gain a general description of the people who participate in the survey.

Throughout this questionnaire the term ‘caree’ will be used to refer to the person with Parkinson’s disease whom you care for.

Please tick or make a mark in the box that most appropriately answers the question.

1. What is your gender?  Male  Female

2. What is your age?  _________________ years

3. What is your marital status?  Single  Married  Divorced  De Facto  Widowed

4. How long have you been in your current relationship?  ________________ years

5. What is the relationship between you and the caree? Eg. Is the caree your spouse, auntie, friend etc.

   Spouse  brother/sister

   Auntie, Uncle  Niece/Nephew

   Cousin  Friend

   Other  Please Specify  ____________________________

6. How long have you been caring for the caree?  ________________ years.

7. How long have you known the caree for?  ________________ years.
8. How close or far away from you does the caree live? Is she/he:

- In the same house  
- In a household connected to yours  
- Within walking distance  
- Within the same city/suburb  
- In another city/suburb  
- Other, Please Specify: __________________

9. Are you paid for your work as a carer?  
- Yes  
- No  

10. During the past week, about how many hours have you spent providing care?  
_______________ hrs.

11. How many hours would you currently receive formal services whether inside (eg. homemaker services to help with housework, personal care tasks, meal preparation, in home nursing etc.) or outside (e.g. adult day care, transportation, therapy services, caregiver support group) the home?  
_______________ hrs/week.

12. How long since the caree was diagnosed with Parkinson’s disease? ________________ years.

13. How long since the caree first noticed symptoms of Parkinson’s disease? ________________ years

14. What is your place of birth?  
- Australia  
- New Zealand  
- UK  
- Asia  
- Europe  
- Other  
- Please Specify ________
15. Where do you currently live?  
- Australia  
- New Zealand  
- UK  
- Asia  
- Europe  
- Other  
Please Specify ____________

16. What is your current postcode/zipcode? ____________________________

17. Is English your first language?  
- Yes  
- No


19. What is/was your occupation? ________________________________.

20. What is the highest educational level you have achieved?  
- Primary  
- Some secondary  
- Secondary completed  
- Trade qualification  
- Tertiary level  
- Postgraduate

21. Do you have serious medical conditions?  
- Yes  
- No

If yes, please specify  ________________________________

22. Does your caree have any other serious medical conditions?  
- Yes  
- No

If yes, please specify  ________________________________.
This section is about your quality of life as a care-giver.

1. Have you continued at your former place of work after your relative (or caree) fell ill?
   Yes   No

   Please tick one or more of the following if they apply:
   - Full-time, for full working day
   - Part-time with incomplete working day
   - Had to start working (if hadn’t worked before)
   - Didn’t work before either

2. Do you manage to perform your duties while now being occupied with the patient’s (caree’s) care?
   Yes   No

   Please tick one of the following:
   - As well as previously
   - With difficulty
   - Partly manage
   - Not at all

3. Did you change your work because of your relative’s (or caree’s) disease?
   Yes   No

   If yes, your job is now:
   Please tick one or more of the following:
   - The same as previously
   - Close to previous type
   - In another branch
   - Changed job for other reasons not related to the relative’s disease
4. Are you obliged to perform any complementary job for extra money?

Yes         No

Please tick one of the following:

- As frequently as before
- Rarely
- Somewhat less
- Often
- Very frequently
- Never

Performance other job for reasons unconnected to the relative’s (caree’s) disease

5. Do you have time for different kinds of leisure activities in spite of your involvement into the patient’s (caree’s) care?

Yes         No

Please tick one of the following:

- As frequently as before
- Somewhat more than before
- Somewhat less than before
- Rarely
- Never
- Never did
6. Does care of the patient (caree) allow you to run the household?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Now I have more to do</th>
<th>As much as previously</th>
<th>Somewhat less</th>
<th>Very Rarely</th>
<th>Never</th>
<th>Never did</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Buying food</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2. Making laundry</td>
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<td></td>
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<tr>
<td>3. Cleaning house</td>
<td></td>
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<td></td>
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<tr>
<td>4. Cooking</td>
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<tr>
<td>5. Other Please Specify:</td>
<td></td>
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</tr>
</tbody>
</table>

7. Does care of patient (caree) allow you to give a hand to your parents and other relatives?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

Please tick one of the following:

- More frequently than before as I have now stopped work
- As frequently as before
- Somewhat less frequently
- Very rarely
- Never
- Never did
- More frequently than before as now it is my responsibility
8. Do you continue to discuss family plans and problems with your ill relative (or caree)?

Yes  □  No  □

Please tick one of the following:

□ More often than before
□ As often as before
□ A little less often than before
□ Very rarely
□ Never
□ Never did before

9. Does the care of your relative (or caree) let you to continue to attend to the needs of your children or the grandchildren as well as you did before?

Yes  □  No  □

More frequently than before as I have now stopped work
As frequently as before
Somewhat less frequently
Very rarely
Never
Never did
More frequently than before as now it is my responsibility

1. To control and help children in scholarship

2. To take children to school, to sport activities or for a walk

3. To take children to theaters, museums, etc.

4. Other Please Specify:
10. Does the regular everyday care and attention to the chronically disabled person (caree) make you depressed?

Yes [ ] No [ ]

Please tick one of the following:

- The mood is the same as before
- Continuous depression (a week or more)
- Stable depression with weight loss and insomnia
- Depression for reasons unconnected with relative’s disease

11. Can the patient (caree) stay at home by themselves while the family members are out or away?

Yes [ ] No [ ]

Without assistance he/she is able to:

1. Dress
   - Always
   - Sometimes
   - Never

2. Make the bed
   - Always
   - Sometimes
   - Never

3. Warm up food
   - Always
   - Sometimes
   - Never

4. Take food left for him/her (wrapped up or in a container)
   - Always
   - Sometimes
   - Never

12. Does your patient (caree) need assistance when using public transport or car-driving?

Yes [ ] No [ ]

Please tick one or more of the following:

- Never needs assistance
- Somewhat more often than before
- Very often
- Always needs assistance
- Needed assistance before disease started
13. Can your patient (caree) regularly take the prescribed medicine by themselves?  
Yes   ☐   No   ☐  

Please tick one of the following:  
☐ Always  
☐ Sometimes  
☐ Never  

14. Can your relative (or caree) take a bath without assistance?  
Yes   ☐   No   ☐  

Please tick one of the following:  
☐ Always  
☐ Sometimes  
☐ Never  

15. Can your patient (caree) move around without assistance?  
Yes   ☐   No   ☐  

Without assistance he is able to:  

Please tick one box for each question.  

1. Visit his/her therapist  
☐ Always  ☐ Sometimes  ☐ Never  

2. Go for a walk or shopping  
☐ Always  ☐ Sometimes  ☐ Never  

3. Move around inside the whole house  
☐ Always  ☐ Sometimes  ☐ Never  

4. Go to the lavatory  
☐ Always  ☐ Sometimes  ☐ Never  

5. Get seated on the bed  
☐ Always  ☐ Sometimes  ☐ Never
16. Can your relative (or caree) call for a physician by themselves?

Yes   No  

Tick one of the following:

- Always
- Sometimes
- Never

This section is about the amount of burden that you experience as a result of caregiving.

Please tick one box for each question.

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My care receiver (caree) needs my help to perform many daily tasks</td>
<td></td>
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<td></td>
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<tr>
<td>2. My care receiver (caree) is dependent on me</td>
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<tr>
<td>3. I have to watch my care receiver (caree) constantly</td>
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<tr>
<td>4. I have to help my care receiver (caree) with many basic functions</td>
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<tr>
<td>5. I don’t have a minute’s break form my care-giving chores.</td>
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<tr>
<td>6. I feel that I am missing out on life</td>
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<td>7. I wish I could escape from this situation.</td>
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<tr>
<td>8. My social life has suffered</td>
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<tr>
<td>9. I feel emotionally drained due to caring for my care receiver (caree)</td>
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<tr>
<td>10.</td>
<td>I expected that things would be different at this point in my life</td>
<td></td>
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<tr>
<td>11.</td>
<td>I’m not getting enough sleep</td>
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<tr>
<td>12.</td>
<td>My health has suffered</td>
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<tr>
<td>13.</td>
<td>Care-giving has made me physically sick</td>
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<tr>
<td>14.</td>
<td>I’m physically tired</td>
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<tr>
<td>15.</td>
<td>I don’t get along with other family members as well as I used to</td>
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<tr>
<td>16.</td>
<td>My care-giving efforts aren’t appreciated by others in my family</td>
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<td>17.</td>
<td>I’ve had problems with my marriage</td>
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<td>18.</td>
<td>I don’t do as good a job at work I used to</td>
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<tr>
<td>19.</td>
<td>I feel resentful of other relatives who could but do not help</td>
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<td>20.</td>
<td>I feel embarrassed over my care receiver’s (caree’s) behaviour</td>
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<tr>
<td>21.</td>
<td>I feel ashamed of my care receiver (caree)</td>
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<tr>
<td>22.</td>
<td>I resent my care receiver (caree)</td>
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<tr>
<td>23.</td>
<td>I feel uncomfortable when I have friends over</td>
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<tr>
<td>24.</td>
<td>I feel angry about my interactions with my care receiver (caree)</td>
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</tbody>
</table>
This section is about the social support you have in your life. Please tick one box for each question.

<table>
<thead>
<tr>
<th></th>
<th>Very strongly disagree</th>
<th>Strongly disagree</th>
<th>Mildly disagree</th>
<th>Neutral</th>
<th>Mildly agree</th>
<th>Strongly agree</th>
<th>Very strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. There is a special person who is around when I am in need.</td>
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<tr>
<td>2. There is a special person with whom I can share joys and sorrows.</td>
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<tr>
<td>3. My family really tries to help me.</td>
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<tr>
<td>4. I get the emotional help and I need from my family.</td>
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<tr>
<td>5. I have a special person who is a real source of comfort to me.</td>
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<tr>
<td>6. My friends really try to help me.</td>
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<tr>
<td>7. I can count on my friends when things go wrong.</td>
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<tr>
<td>8. I can talk about my problems with my family.</td>
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</tr>
<tr>
<td>9. I have friends with whom I can share the joys and sorrows.</td>
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<td></td>
</tr>
</tbody>
</table>
10. There is a special person in my life who cares about my feelings.

11. My family is willing to help me make decisions.

12. I can talk about my problems with my friends.

This section is about how you feel about yourself. Please note that there are no right or wrong answers. Please report what you feel best describes you.

Please tick one box for each question.

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel that I am a person of worth, at least on an equal basis with others</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>2. I feel that I have a number of good qualities</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>3. All in all, I am inclined to feel that I am a failure</td>
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<tr>
<td>4. I am able to do things as well as most other people.</td>
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<tr>
<td>5. I feel I do not have much to be proud of.</td>
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<tr>
<td>6. I take a positive attitude toward myself.</td>
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<tr>
<td>7. On the whole, I am satisfied with myself.</td>
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<tr>
<td>8. I wish I could have more respect for myself.</td>
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<tr>
<td>9. I certainly feel useless at times.</td>
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</tr>
<tr>
<td>10. At times I think I am no good at all.</td>
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</tr>
</tbody>
</table>
This section is about the caree’s behavioural problems. Please indicate the frequency of occurrence of the following problems.

**Please tick one box for each question.**

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>frequently</th>
<th>all the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Makes physical attacks (eg. hits, bites, kicks, spits)</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>2. Wanders during the day</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>3. Wanders during the night</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>4. Does not cooperate in taking medications</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>5. Requires constant supervision or direction</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>6. Is incontinent</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>7. Makes unwarranted accusations</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>8. Loses/misplaces/hides things</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>9. Sleeps excessively during the day</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>10. Asks the same questions over and over.</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

This section is about your caree’s thought processes. Please tick one box for each question.

<table>
<thead>
<tr>
<th></th>
<th>Present</th>
<th>Absent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Impaired level of consciousness (e.g. awareness of self)</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>2. Impaired attention span (e.g. easily distractible)</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>3. Impaired or confused thinking</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
4. Impaired calculation ability

5. Impaired intelligence

6. Disoriented to person (e.g. fails to remember names and faces)

7. Disoriented on place (e.g. fails to remember places and directions)

8. Disoriented on time (e.g. difficulty remembering time and dates)

9. Impaired short term memory (e.g. what happened recently eg. What they have done over the last 24hrs)

10. Impaired long term memory (e.g. what happened over the past few years/childhood)

11. Denies presence of psychological problems

12. Blames others or circumstances for problems

13. Impaired ability to make routine decisions

14. Impaired impulse control (e.g. engages in activities without consideration of the consequences)
This section is about which activities you get a break for and on average how often you would receive a break in this way.

Please tick which of the following activities gives you a break from care-giving and on average how often you would receive a break in this way:

1. **Running errands, such as shopping or going to the bank?**

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

How often do you get a break in this way? Tick one of the following:

- Never
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more

2. **Doing things around the house such as dishes or tidying up?**

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

How often do you get a break in this way? Tick one of the following:

- Never
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more
3. Doing things for, or taking care of other people in your life other than the caree?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

How often do you get a break in this way? Tick one of the following:

- **Never**
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more
- Once per week

4. Doing things for, or taking care of yourself (e.g. Baths, haircuts, massage).

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

How often do you get a break in this way? Tick one of the following:

- **Never**
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more
- Once per week

5. Getting physical exercise or doing recreational activities. (e.g. yoga, walking, golf)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

How often do you get a break in this way? Tick one of the following:

- **Never**
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more
- Once per week
6. Doing hobbies such as art, woodwork, gardening etc.

Yes [ ] No [ ]

How often do you get a break in this way? Tick one of the following:

- Never
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more

7. Pursuing leisure activities, such as games, cards, going on picnics, etc.?

Yes [ ] No [ ]

How often do you get a break in this way? Tick one of the following:

- Never
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more

8. Going to movies, plays, concerts, art galleries, or other cultural events?

Yes [ ] No [ ]

How often do you get a break in this way? Tick one of the following:

- Never
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more
9. Listening to music, watching TV, or reading?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

How often do you get a break in this way? Tick one of the following:

- Never
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more
- Few times a year
- Once a month
- 2-3 times a month
- Once per week

10. Talking about your feelings or experiences with others?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

How often do you get a break in this way? Tick one of the following:

- Never
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more
- Few times a year
- Once a month
- 2-3 times a month
- Once per week

11. Talking about your feelings or experiences with other caregivers?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

How often do you get a break in this way? Tick one of the following:

- Never
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more
12. Socializing informally with others, such as going to lunch, coffee, or get-togethers?

Yes [ ]  No [ ]

How often do you get a break in this way? Tick one of the following:

- Never
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more

13. Participating in organised social activities such as clubs?

Yes [ ]  No [ ]

How often do you get a break in this way? Tick one of the following:

- Never
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more

14. Having time alone or time to yourself?

Yes [ ]  No [ ]

How often do you get a break in this way? Tick one of the following:

- Never
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more
15. Having time to sleep or rest?

Yes □ No □

How often do you get a break in this way? Tick one of the following:

- Never
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more

16. Having a vacation, getting away for a while?

Yes □ No □

How often do you get a break in this way? Tick one of the following:

- Never
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more

17. Engaging in spiritual activities, such as prayer or other such activities?

Yes □ No □

How often do you get a break in this way? Tick one of the following:

- Never
- Few times a year
- Once a month
- 2-3 times a month
- Once per week
- Twice per week
- 3-4 times per week
- 5-7 times per week
- Twice a day or more
18. Going to work or school or volunteering?

Yes   No

How often do you get a break in this way? Tick one of the following:

- Never
- Twice per week
- Few times a year
- 3-4 times per week
- Once a month
- 5-7 times per week
- 2-3 times a month
- Twice a day or more
- Once per week

19. Getting involved in a project or endeavour that requires “brain work” e.g. studying or reading to learn?

Yes   No

How often do you get a break in this way? Tick one of the following:

- Never
- Twice per week
- Few times a year
- 3-4 times per week
- Once a month
- 5-7 times per week
- 2-3 times a month
- Twice a day or more
- Once per week

20. Is there anything else that gives you a break or that would give you a break?

Yes   No

How often do you get a break in this way? Tick one of the following:

- Never
- Twice per week
- Few times a year
- 3-4 times per week
- Once a month
- 5-7 times per week
- 2-3 times a month
- Twice a day or more
- Once per week
This section is about the caree’s activities of daily living. Please rate the caree’s level of dependence by ticking one box for each question.

<table>
<thead>
<tr>
<th></th>
<th>Independent</th>
<th>Some help required</th>
<th>Completely dependent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Eating</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Dressing/undressing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Getting about the house</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>4. Getting in and out of bed</td>
<td></td>
<td></td>
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<tr>
<td>5. Taking a bath or shower</td>
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<td></td>
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<tr>
<td>6. Using the toilet</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>7. Using the telephone</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>8. Going shopping for groceries or clothes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Preparing meals</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Doing heavy housework and laundry</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>11. Doing light housework</td>
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<td></td>
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<tr>
<td>12. Doing yard work</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>13. Taking medication</td>
<td></td>
<td></td>
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<tr>
<td>14. Managing money day-to-day</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Handling long-term finances</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
This section is about your relationship with the caree. Please tick one box for each question.

1. How well does your partner meet your needs?
   - Not at all
   - Slightly
   - Moderately
   - Considerably
   - Extremely

2. In general, how satisfied are you with your relationship?
   - Not at all
   - Slightly
   - Moderately
   - Considerably
   - Extremely

3. How good is your relationship compared to most?
   - Much worse
   - Not as good
   - About the same
   - Better
   - Much better

4. How often do you wish you hadn’t gotten into this relationship?
   - Never
   - Seldom
   - Sometimes
   - Often
   - Very often

5. To what extent has your relationship met your original expectations?
   - Not at all
   - A little
   - Moderate
   - Considerable
   - Very much

6. How much do you love your partner?
   - Not at all
   - A little
   - Average
   - Quite a bit
   - Very much

7. How many problems are there in your relationship?
   - Hardly any
   - Less than average
   - About average
   - More than average
   - A great many
This is an opportunity for you to tell us more about care-giving for a caree with Parkinson’s disease. It would be very much appreciated if you could take the time to respond to these questions in writing.

1. What are the positive aspects of caregiving?

2. What are the negative aspects of caregiving?

3. How do these positive and negative aspects of caregiving affect your quality of life?

4. Is there anything you wish that you could change about your caregiving experience?

5. How do you feel Parkinson’s disease has affected the relationship with your caree?

Please return the questionnaire to us in the prepaid addressed envelope provided.

Thank you for your participation.