

CHAPTER ONE

GENERAL INTRODUCTION

1.1 Scope and aims of thesis

The aim of this dissertation is to investigate the workplace experience of people with Parkinson's disease. Specifically, it aims to provide a descriptive account of what it is like to work with Parkinson's and to identify the work related factors that have most influence on the psychological well-being and Quality of Life (QoL) of people with Parkinson's following diagnosis. By furthering knowledge about how Parkinson's affects employment, this study will contribute to the development of appropriate sources of information and effective interventions to improve the experience of those living with Parkinson's that choose to remain in the paid workforce.

During the past decade a few research projects have emerged focusing on the work related issues of people with Parkinson's (PWP). This is no doubt due to a growing awareness of Parkinson's disease in general and, in particular, an awareness that Parkinson's is not only a disease of the elderly but also a condition affecting those of working age. A broader awareness of a particular medical condition increases the likelihood of earlier diagnosis. Since many people have had Parkinson's for up to fifteen years or more before it is correctly diagnosed, it may be that during those fifteen years they have transitioned from the workforce to retirement. Earlier diagnosis would therefore mean that there would be increasingly more individuals who have to address the implications of working with a Parkinson's diagnosis than there have been in the past.

The need for research in this area has therefore become apparent in order to address the economic as well as psychosocial impact of Parkinson's. In an Australian context, research into Parkinson's and employment fits neatly into contemporary concerns about an ageing population that have led to debates about issues such as raising the retirement age.

The aim of the current chapter is to describe Parkinson's disease from a diagnostic point of view as well as present a comprehensive picture of what it is like to live with Parkinson's. Clearly an assessment of the principal physiological symptoms experienced by a patient is important in order to monitor the progress of the condition and its response to medication. However, it is now widely accepted that what also matters is how a disease affects a person's day-to-day life and their ability to function

both socially and psychologically. This chapter concludes with a review of psychosocial research relating to PWP, focussing on the age group more likely to be in the workforce, that is, a younger cohort.

Chapter Two reviews the literature pertaining to Parkinson's and QoL and tries to identify material that is relevant to PWP in the workplace. The focus of Chapter Three is Parkinson's and employment and, due to the paucity of literature in this area, incorporates research relating to other chronic conditions and employment. The final chapter of the introduction examines findings in relation to employment and healthy populations and presents one of the dominant models used in the area of workplace stress, the Job Strain Model (JSM).

Chapter Five introduces a qualitative study which tries to identify the factors that are most important to PWP in the workplace through six semi-structured interviews. This chapter presents the method, results and conclusion from this initial study. Chapter Six introduces and reports results of a larger, quantitative study, a survey of 116 PWP, discussing the implications in relation to previous research.

A concluding section, Chapter Seven, discusses the broader application of this research and offers recommendations as to how the results can be used to improve the lives of PWP in the workforce. By way of introduction to the focus of this research, there now follows a description of Parkinson's disease, its cause, progression and prevalence.

1.2 Parkinson's Disease

Parkinson's disease is a degenerative neurological disease that was first described as a set of symptoms constituting a single condition by its namesake, James Parkinson, in his essay *The Shaking Palsy* in 1817 (Neylan, 2002). Parkinson's disease is now more commonly referred to as 'Parkinson's' or 'Parkinson', distancing the condition from any perception that it may be an infectious disease. For the purposes of this study Parkinson's disease will henceforth be referred to as 'Parkinson's'.

Parkinson's is characterised by a deficit in levels of dopamine, a neurotransmitter that is produced in part of the brain called the substantia nigra. Parkinson's is also characterised by the presence of Lewy bodies in the substantia nigra and other parts of the brain. Dopamine is responsible for controlling movement by assisting transmission of neurological signals from the substantia nigra to the corpus striatum (Marjama-Lyons & Koller, 2001; Samii, Nutt, & Ransom, 2004). Correct

functioning of the corpus striatum is necessary for an individual's smooth muscular movements. The imbalance in neurotransmitters caused by depleted levels of dopamine in a brain affected by Parkinson's results in the malfunction of the corpus striatum and this affects muscular activity. The chemical imbalance caused by depleted levels of dopamine also stimulates the medial segment of the globus pallidus, leading to bradykinesia (slowness in movements). Figure 1 below depicts the parts of the brain involved in Parkinson's.

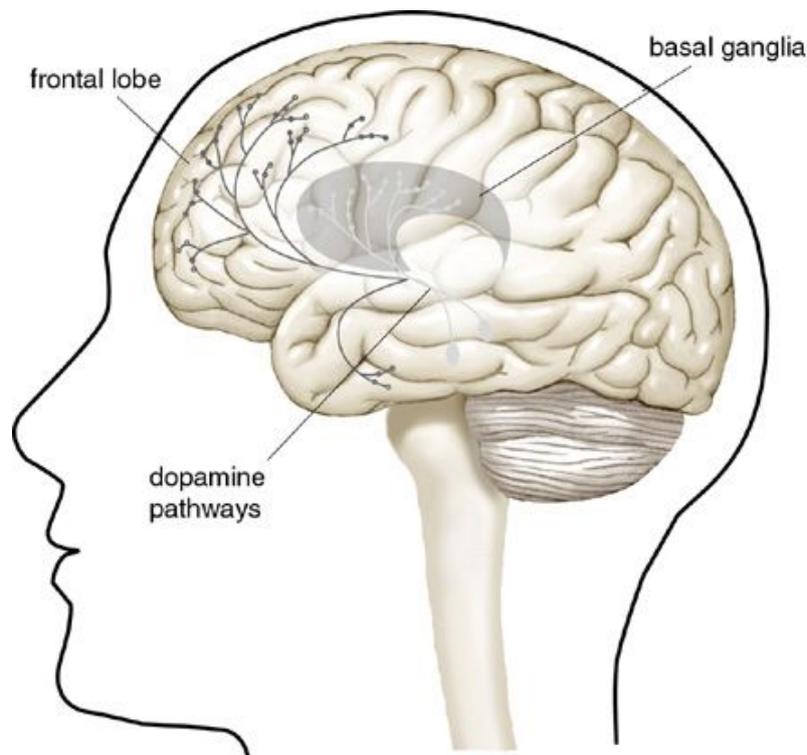


Figure 1. Brain Structures Implicated in Parkinson's (www.nobelprize.org retrieved 24 September 2009)

1.3 Cause and progression

There is no single identified cause of Parkinson's and, similarly, no definite sequence of progression. In some cases the condition may result from oxidative damage or follow environmental exposure or head injury (Samii et al., 2004). There is a genetic component of Parkinson's in an estimated 15-20% of cases. Parkinson's is most likely to occur between the ages of 40 and 70 years (Sami et al., 2004).

The progression of an individual's Parkinson's bears some relationship to the age of onset and likely cause. This information is therefore of some assistance when

designing an individual's treatment. However, such information is by no means foolproof. The only certainty with Parkinson's in terms of progression is that the condition will deteriorate over time with increasing limitations to daily function (Marjama-Lyons & Koller, 2001; Samii et al., 2004; Springer-Verlag, 2003).

1.4 Prevalence

Parkinson's is the second most common neurological condition in Australia. There are an estimated 53,200 to 72,200 Australians with Parkinson's (Access Economics, 2007), the majority of whom are diagnosed between the ages of 50 and 75 years ($M = 60$ years). At any one time, 18% of PWP are estimated to be of working age (15-64 years). Ten percent of PWP receive their diagnosis when they are under the age of 40 and 15% under the age of 50.

Parkinson's is non-discriminatory in terms of gender, race and economic status (Samii et al., 2004). It is estimated that 10-20% of PWP are living in the community undiagnosed (Schrag, Ben-Shlomo, & Quinn, 2000). The ageing population combined with a growing knowledge of the symptoms amongst general practitioners and the public mean that diagnosis is likely to be made earlier in the progression of the condition. This means that numbers of PWP who are working at the time of diagnosis are likely to increase, and research in this area is timely.

1.5 Diagnostic symptoms

There are four cardinal symptoms of Parkinson's used in diagnosis; tremor, rigidity, bradykinesia (slowness of movement) and postural instability (Duvosin, 1984; Marjama-Lyons & Koller, 2001; Samii et al., 2004). The characteristics of these symptoms are outlined in Table 1.

Table 1.

Characteristics of Four Cardinal Symptoms of Parkinson's Disease

Symptom	Characteristics
Tremor	Typically unilateral in initial stages in resting arm and/or leg. Tremor is not always present. Differentiated from essential tremor which occurs when limbs are used and also affects the voice and head.
Bradykinesia	Slowness of movement, identified as difficulty rising from a chair, decreased arm swing, dragging one leg, small and shuffling gait and a stooped posture. Progresses to freezing whilst walking and reduction in rate of blinking, facial expressions and gesturing.
Rigidity	Initially more pronounced unilaterally and most easily identifiable by flexing, extending and rotating at joints.
Postural instability	Usually present in latter stages of Parkinson's and visible when patient does not respond in order to rectify incorrect balance.

Preliminary diagnosis is dependent on the presence of one or more of these symptoms, in any combination, but only confirmed upon a positive response to dopamine enhancing medications. Other physical symptoms that aid diagnosis are micrographia (very small and often illegible handwriting), fatigue, absence of an arm swing or the dragging of a lower limb when walking and a reduction in vocal volume. As Parkinson's progresses symptoms may include a characteristic 'masked face' due to inactivity of facial muscles. Speech difficulties often occur affecting both articulation and volume. As the condition progresses, PWP may experience impairment to the Autonomic Nervous System leading to dribbling, an inability to initiate movement, difficulty swallowing, constipation and impotence. Impairment to cognitive function may also be present leading to difficulties in organising thoughts and concentration. PWP also have to contend with increasingly disruptive levels of fatigue.

Although medications such as dopamine agonists and levodopa are able to alleviate symptoms they are subject to tolerance and are ineffective in the long-term as the condition progresses. PWP live with increasingly difficult physical problems that inevitably have a corresponding psychosocial impact.

1.6 Treatment

Following diagnosis, decisions need to be made as to how to treat the symptoms of Parkinson's so as best to accommodate personal circumstances and day-to-day activities (Marjama-Lyons & Koller, 2001; Samii et al., 2004). It is vital to tailor treatment to the particular needs of an individual. For example, a person with bradykinesia, who is active in manual employment and possibly the main income earner in a growing family, needs sufficient medication to allow him to continue to work. In contrast, someone who receives a diagnosis who is already retired and whose only symptom is a resting tremor may not need medication until symptoms progress.

Medication involves numerous decisions, as there are a growing number of pharmacological options, all with consequential benefits but also side effects. The most common first medications used are dopamine agonists which, in about 30% of cases, have been found to control tremor, rigidity and bradykinesia for a period of about five years (Marjama-Lyons & Koller, 2001; Samii et al., 2004). Side effects of dopamine agonists are common and can include hallucinations, confusion, hypotension, nausea, difficulties with impulse control (e.g. leading to problem gambling) vomiting and daytime sleepiness, to which older patients have less tolerance than younger people. (Marjama-Lyons & Koller, 2001; Rubenis, 2007).

In many patients symptoms are not sufficiently controlled with dopamine agonist alone so levodopa is also prescribed. Despite levodopa's effectiveness in reducing cardinal symptoms such as tremor and rigidity, the majority of patients receiving it develop motor complications such as dyskinesia. Other medications are used as adjuncts to these primary treatments in order to reduce the side effects that are hard to tolerate or to address non-motor symptoms such as depression and constipation.

PWP have also been found to benefit from non-pharmacological treatments such as physiotherapy, occupational therapy, speech therapy, assistance with nutritional needs and complimentary therapies such as massage, tai chi and yoga (Marjama-Lyons & Koller, 2001; Samii et al., 2004). Surgical interventions such as deep brain stimulation and pallidotomy are generally only available for patients with severe motor

fluctuations or dyskinesia. These approaches entail risks associated with any brain surgery and provide no certainty about the longevity of their effectiveness (Rubenis, 2007; Springer-Verlag, 2003).

With such an array of symptoms, side effects and possible pharmacological and non-pharmacologic treatments it seems obvious that it may take some time to find the most appropriate options for a particular individual with Parkinson's. The progression of the condition means that any satisfactory treatment option is only going to be effective for a limited period of time before the symptoms change and treatment needs to be reviewed. Treatment of Parkinson's is a time consuming, costly and often distressing process and, although physical symptoms may be alleviated, it is possible that the process of treatment itself may have a negative impact on a person's QoL.

Two factors to be considered when designing a treatment plan for a person with Parkinson's are their age and life stage at the time of diagnosis. Consideration of life stage necessarily includes an evaluation of a person's need to be engaged in full- or part-time work and how this may affect the management of their condition.

1.7 Psychosocial impact

PWP have reported that the psychosocial aspects of the condition have a greater negative impact on their lives than the physical symptoms (Abudi et al., 1997; Brod, Mendelsohn, & Roberts, 1998; Cubo et al., 2002; Frazier, 2000; Schrag, Jahanshahi, & Quinn, 2000; Schreurs, De Ridder, & Bensing, 2000; Suzukamo et al., 2006). For instance, an estimated 40% of PWP experience depression (Dakof & Mendelsohn, 1986; Rao, Hubert, & Bornstein, 1992) but it remains unclear as to whether depression forms part of the condition or is an understandable consequence of it. Treatments for Parkinson's have typically focussed on attending to the physical symptoms whilst paying scant regard to the psychosocial impact of the illness. Shulman et al. (2002) found that neurologists treating Parkinson's patients failed to diagnose depression and anxiety in over half of their patients and overlooked sleep disturbances in 40% of those under their care. This means that many PWP are enduring psychological distress for which they are receiving no treatment.

The physical limitations of Parkinson's lead to increasing dependence on others and inevitable changes in roles and relationships (Schrag et al., 2000; Schreurs et al., 2000). Schrag et al. found that PWP experienced more problems in social functioning than their aged matched counterparts in the general population. Difficulties related to

problems with transportation and communication, as well as limitations to participation in social activities such as eating in public and playing sport. Strangers often misinterpret the appearance of PWP as being that of someone who is either drunk or has a mental illness and treat them as such, thus making socialising in public a difficult or even humiliating experience (Abudi et al., 1997; Lyons & Tickle-Degnen, 2003).

Incidents of crying, falling, dribbling or being misunderstood in public can cause embarrassment and shame and lead PWP to become extremely anxious about such incidents taking place (Nijhof, 1995). These experiences, or the possibility of them occurring, obviously have implications for work life if an individual is still in employment. PWP may gradually find themselves confining themselves to the home environment where relationships with partner and family can become overly intense and strained, especially when the partner is a full-time carer (Dakof & Mendelsohn, 1986; Ellgring et al., 1993; Hodgson, Garcia, & Tyndall, 2004; Nijhof, 1995). The impact of this may be different depending on the life stage at which PWP receive their diagnosis.

1.8 Early onset Parkinson's

There is much dispute as to the division between early and later onset Parkinson's (Calne, Lidstone, & Kumar, 2008). The categorisation is deemed necessary because of observed differences in the sequence of symptoms and rate of progression depending on age of onset. A further distinction between early and late onset Parkinson's has seemed necessary due to the differing psychosocial impact of the condition. Defining early onset as being diagnosis under the age of 50, Schrag et al. (2003) found that this section of the Parkinson's population experienced more problems with stigma, marital relationships and employment than their older counterparts.

The socio-economic impact of Parkinson's is greater for younger people than older individuals (McQuillen, Licht, & Licht, 2003). They may have families, mortgages and be many years from even starting a retirement plan, let alone enacting it. As a result, younger PWP are more likely to experience depression and feel more stigmatised than older people (Calne et al., 2008). Younger PWP are likely to be more concerned with career advancement than early retirement and feel discouraged knowing that deterioration of their condition is inevitable. Retraining to accommodate lesser function may be demoralising since the uncertain progression of the condition may mean that what was possible when planning retraining is no longer possible once the

training is complete. Young PWP may face complications at work that are difficult to accept as appropriate to their age.

In order to control symptoms at work, PWP who wish or need to maintain employment are often on higher levels of medication than those not working (Calne & Kumar, 2008). Those not working may not be so concerned about hiding or minimising symptoms such as tremor. In order to manage symptoms for those still working, medications are often combined leading to additional side effects (e.g., bradykinesia, hallucinations), and these also need to be managed.

The few psychosocial studies into the impact of Parkinson's on those in a younger demographic highlight the need for further research into Parkinson's as experienced by this population. Research needs to address issues that are more salient to a younger demographic such as sexuality and employment. Most psychosocial research into Parkinson's has been carried out using a broad age range reaching into 80s, thus reducing the significance of concerns of particular importance to younger people. Schrag et al. (2003) noted the difficulties associated with obtaining an adequate sample for research into issues affecting younger people with Parkinson's. The majority of psychosocial research into Parkinson's disease uses samples obtained through Parkinson's support groups and, since older people generally have fewer obligations (work, family etc.), those no longer in the workforce may be over-represented in the samples. As a result psychosocial research into Parkinson's has rarely focused on the role of work in the lives of those who have the disease. Recent studies (e.g., Access Economics, 2007; Zesiewicz et al., 2007) have taken an economic perspective on Parkinson's and employment. This has resulted from the growing awareness of the financial implications of managing the condition. Others have focused on change at work post-diagnosis and the maintenance of employment (Banks & Lawrence, 2006; McCabe, Roberts, & Firth, 2008; Martikainen, Luukkaala & Marttila, 2006; Schrag & Banks, 2006). There is no research focussing on the relationship between the work experience of PWP and their psychological well-being and QoL.

1.9 Parkinson's and employment

An estimated 16% of PWP in Australia are of working age (Access Economics, 2007). Access Economics estimated the productivity costs associated with Parkinson's for 2005 to be \$55.2 million. Although these costs also include absenteeism and premature mortality, they are primarily made up of the cost of employees leaving work

prematurely. Although the economic burden of a disease may be influential in swaying governments into action in order to reduce unnecessary expenditure, a monetary figure does not capture the impact of loss of productivity on a person's QoL. Loss of employment necessarily incurs a loss of income, social interactions and independence that together cannot fail to have negative consequences in terms of self-esteem and general psychological health. To date, only one Australian study exists evaluating the impact of Parkinson's on employment (McCabe et al., 2008).

In their research, McCabe et al. (2008) incorporated Parkinson's as one of four progressive neurological conditions that lead to extensive changes in employment status (other conditions were Multiple Sclerosis (MS), Huntington's disease (HD) and motor neurone disease (MND)). Interviews were conducted with individuals living with these conditions, but also with carers and health professionals working in this area. Of the 138 individuals interviewed in this study, 31 were PWP (age $M = 63.30$ years), eight were carers of PWP and eight were professionals who worked with PWP. Results were similar for individuals living with each of the four conditions under investigation.

McCabe et al. (2008) found that the majority of patients with one of the four neurological conditions had moved from full-time work to unemployment as a result of their illness and in most cases had resigned due to their inability to meet the demands of their job. Others had either been made redundant or could not find a new job. Those patients who had moved from full-time into part-time employment also cited problems in coping with the demands of their work as being responsible for this change, but talked specifically of the negative impact of fatigue on their ability to maintain full-time employment.

The view held by some health professionals working with progressive neurological conditions was that many individuals left work prematurely rather than taking on a part-time role and suffered as a result of this change (McCabe et al., 2008). The majority of patients also felt negatively about losing their employed status. They cited a range of consequences to leaving employment including frustration, depression, anger and grief. Patients also talked of the financial strain imposed by loss of work and the negative impact that this had on social activities outside work.

McCabe et al. (2008) concluded that efforts needed to be increased to assist in maintaining employment for people with progressive neurological conditions for as long as possible. The specific target of interventions aimed at prolonging employment was not addressed by McCabe et al.. Their research, though groundbreaking, sourced

participants solely from support agencies for people with neurological conditions, thus restricting the generalizability of their results. Interviews were conducted with individuals who were not necessarily still working, therefore relying on memory rather than being an account of the employment as they were experiencing it at the time the research was conducted. The current research aimed to address these limitations by diversifying the source of participants, and limiting the sample to those that are currently working. This would inevitably lower the mean age of the research sample. This research was also designed to provide quantitative evidence to support qualitative findings.

Reference to international studies undertaken into Parkinson's and employment may be misleading since each country has its particular provisions for disability support and is governed by differing discrimination legislation. However, in the absence of further Australian based research, a review of the literature emanating from overseas may be instructive. Such a review reveals some consistency in the pattern for remaining, changing or leaving work but no consistency in the reasons behind the employment status outcome.

Two United Kingdom (UK) based studies have found that on average PWP stay in employment 4.9 years following the onset of symptoms (6.7 years for those with onset before the age of 45) (Schrag & Banks, 2006). However, there was a wide range in the time that people remained in employment, from 0-17 years. This range was not explained by reference to gender, place of residence, type of work, marital status or the existence of dependent children as might be expected. Nor was there a significant difference in the proportion of PWP in part-time work and the proportion of people in the general population who worked part-time. Banks and Lawrence (2006) found that out of a sample of 339 PWP of working age, 30.4% were in employment. In order to ascertain the reasons behind withdrawal from work, interviews were conducted with 24 of this cohort. This research provides the most comprehensive account of working with Parkinson's in the literature.

Over 80% of those surveyed cited coping with the symptoms of Parkinson's as having made work difficult for them. A range of specific problems were mentioned, the most common being fatigue and 'slowing down'. Many stated that problems with writing had made work life difficult whilst others said that stiffness in their hands meant that they struggled to use a keyboard or carry out other tasks requiring fine motor skills. Problems with speech, tremor, memory and concentration were also reported as having

a negative effect on their work experience. Psychological difficulties such as anxiety and depression were seldom raised although some participants did talk about increased difficulty dealing with stressful situations.

Banks and Lawrence (2006) found that there was no significant difference in the effect of Parkinson's on employment status between those working in manual and non-manual occupations. Those that were self-employed appeared to have more difficulty with work due to the necessity of being constantly and consistently responsible for their business. Employers emerged as supportive to the majority of those who had provided information about Parkinson's (73.8%). Those who had talked to their employers about their condition stayed on average an extra two years longer in employment than those who did not. Employers were able to help make changes at work, but merely reducing hours worked did not have a significant effect on prolonging employment. One effective way of managing work demands was manipulating drug therapy. Higher doses of medication were sometimes taken on work days or doses were timed so that 'on' periods coincided with work hours. This was reported as the only way that health professionals assisted PWP with regard to their employment. Banks and Lawrence suggested by way of conclusion that PWP of working age were not well informed about the implications of their diagnosis and the choices available to them with regard to work.

A more dismal picture of the prospects of remaining in employment whilst managing Parkinson's exists in the United States of America (USA) (Zesiewicz et al., 2007). Zesiewicz et al. found that 82% of PWP felt too disabled to work after an average of only 3.4 years post-diagnosis. The difference between the UK and USA study may be due to either differing work support programs or the influence of a sample obtained from an academic research centre rather than through support groups. In this American study the primary reasons given for ceasing work were fatigue, stiffness, tremor and bradykinesia. However, the majority of those retiring early reported having jobs that involved public speaking, sales or manual labour. It is possible there may be more issues underlying cessation of work than the physical symptoms reported as being responsible.

In the study referred to above, Zesiewicz et al. (2007) asked no questions about successful management of Parkinson's or the reaction of others to the physical symptoms of the condition. Although type of work was taken into account, those surveyed were not asked about how they perceived their work in terms of the stress that

it imposed on them. Such factors may well have an impact on an individual's confidence to competently do their job and deal with colleagues and clients in the course of employment. Indeed, difficulties in this area may lead many to leave employment. It seems there is a need to further examine the psychosocial impact of Parkinson's on employment rather than focus on physical symptoms alone.

A Finnish study indicated that PWP most commonly left the workforce less than two years following diagnosis (Martikainen et al., 2006). This result presents a more dismal view of employability for PWP than either the UK or USA studies. In contrast to the US study outlined above, departure from employment was not dependent on either the severity of symptoms or associated depression. Martikainen et al. found that being in white collar work was a significant predictor of remaining in employment, as were shorter duration of disease, younger age and less severe symptoms. Staying in employment was also influenced by an individual's capacity to make adjustments to their work and daily routine in order to manage any difficulties presented by Parkinson's.

There is no consistency in the explanations as to why some PWP remain in the workforce and others leave. The focus of research to date has been largely been on demographic and symptomatic factors as well as type of work and these do not give a full picture of the experience of PWP in the workplace. Only one quantitative study was found that addressed the relationship between Parkinson's, employment and QoL (Klepac et al., 2008). Klepac et al. explored the relationship between cognitive performance and QoL in PWP in Croatia and included employment status as one of the patient characteristics to be considered. Consistent with studies investigating employment and QoL for other chronic conditions, those PWP who were working had a significantly better QoL than those who were not working. However, Klepac et al.'s sample of 124 individuals had a mean age of 60.4 and only 25 participants reported themselves to be working. Despite the demographic limitations of this study, it provides evidence of the benefits of employment for PWP in terms of QoL.

Many of the problems faced by workers with Parkinson's are likely to be similar to those problems faced by all people in employment. Others may be similar to those confronted by individuals living with other chronic illnesses. PWP are also likely to experience work related problems that are unique to their condition. Regardless of whether they are common to all workers, shared with others living with chronic illness or specific to PWP, one aim of this research is to identify the psychosocial work related

factors that influence the QoL of PWP. The relative impact of work related factors on worker well-being has not been explored with reference to Parkinson's and this research necessarily needs to be conducted in the context of factors already identified as contributing to QoL of PWP in general.

CHAPTER TWO

PARKINSON'S AND QUALITY OF LIFE (QOL)

The QoL experienced by PWP is inferior to that of people of a similar age in the general population (Karlsen et al., 1998; Quittenbaum & Grahn, 2004). This difference is more marked in younger people.

Schrag et al. (2000) conducted a study specifically comparing the QoL of PWP with that of their age matched healthy counterparts. Schrag's team found that the greatest area of difference between PWP and the general population was in levels of self-care; PWP reported ten times as many problems with self-care than those surveyed who did not have Parkinson's. The differences were most marked in younger people, those under 50 years of age. One explanation for this may be the difference in expectations between older and younger people. Whereas all people experience limitations in their lives as they age, the limitations experienced by younger PWP are in stark contrast to opportunities open to a similarly aged, healthy demographic of people under 50.

One significant difference between older and younger PWP as compared to their healthy age matched counterparts was in reported levels of anxiety and depression (Schrag et al., 2000). As healthy people age, the majority find themselves gradually restricted physically by their ageing bodies or by various health conditions such as arthritis and diabetes whose occurrence increases with age. PWP may therefore experience QoL difficulties in similar ways to any ageing person. In relation to depression and anxiety, however, it is possible that these psychological conditions may be related specifically to the way that dopamine deficiencies affect later onset Parkinson's. Alternatively, perhaps Parkinson's at a later age leads to greater isolation and sense of loss than is generally experienced by people as they age.

2.1 Defining QoL

There are many and varied definitions of QoL and therefore any study using QoL as an outcome measure needs to firmly establish what the concept means in the context of the particular piece of research. The World Health Organisation (WHO) (1995) has established a consensus on certain characteristics of QoL. The first of these characteristics is that a measure of QoL is subjective and represents a person's evaluation of their behaviours, states and capacities as well as an assessment of their

satisfaction with same. This means that a measure of QoL may be very different to a medical practitioner's objective assessment of a patient's level of function.

The second characteristic on which there is consensus is that QoL is a multi-dimensional construct incorporating domains covering at least the physical, psychological and social facets of a person's life. In addition, these domains can be measured on both positive and negative dimensions.

Finally, WHO defined QoL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO, 1995, p. 1405). It is clear from this definition that, when assessing the severity of a person's chronic illness, a measure of QoL reveals a more comprehensive picture of a person's condition than merely a summation of their physical symptoms. It also seems that the most accurate comparisons between individuals' QoL need to be made within a cultural context and that cross-cultural or multi-cultural studies incur difficult methodological issues.

2.2 Parkinson's related QoL

The severity of Parkinson's in terms of its impact on QoL is a relatively recent focus of investigation. A review of research in the area carried out several years ago found only three studies investigating the relationship between the symptoms of Parkinson's disease and measures of QoL (Rubenstein, DeLeo & Chrischilles, 2001). More recently QoL has been given increased attention in the Parkinson's literature. One reason for this is that, if sufficient knowledge is generated in relation to how the condition affects a person's daily experience, appropriate treatments can be designed to improve the lives of PWP.

Health related QoL is not just about physical changes and limitations caused by a condition but is a subjective evaluation of how the condition has affected an individual from an emotional, social and functional point of view in relation to social expectations (WHO, 1995). In other words, a measurement of QoL is not a measure of symptoms or consequences but of how much the symptoms and consequences of a condition bother the person experiencing them. There are numerous measures of QoL and the lack of uniformity in definition and measurement make it hard to compare findings (Den Oudsen, Van Heck, & De Vries, 2007). Furthermore, Den Oudsen et al.'s review of research into QoL in Parkinson's found that the majority of studies did not clearly define the concept of QoL or justify their choice of scale. All but two

studies examined for their review appeared to be assessing the concept of health status rather than QoL as outlined by WHO (1995).

Existing research does, however, allow for some general conclusions about what contributes to QoL in PWP. For instance, in one of the studies that Den Oudsen et al. (2007) identified by as accurately assessing QoL, Lee et al. (2006) found QoL to be related more to the psychosocial impact of the disease than to its severity in terms of symptoms. Reuther et al.'s (2007) longitudinal study over a period of one year concluded that an assessment of Parkinson's related QoL using a disease specific measure is an essential component of assessing the severity of a PWP's condition. The authors of this study were, however, guilty of Den Oudsen et al.'s criticism in failing to clearly define the concept of QoL that was being measured.

Parkinson's has been found to have a significant effect on health related QoL (Herlofson & Larsen, 2003; Koplas et al., 1999; Kuopio et al., 2000; Schrag et al., 2000; Slawek, Derejko, & Lass, 2005). Despite this consistent finding, there are methodological issues with these studies, e.g. failure to describe the sample in terms of age (Herlofson & Larsen), measurement of QoL using responses to a single item (Koplas et al.) or a scale without justification (Kuopio et al.; Schrag et al.; Slawek, Derejko, & Lass). Results of these studies may not be relevant to PWP who are working, as research samples were not confined to a younger Parkinson's demographic.

For the purposes of this current study, a QoL measure was chosen that would meet three criteria. Firstly, the construct was to be measured with a generic scale that would enable any future comparisons with QoL in other populations. Secondly, the scale needed to reflect areas of life that are important to individuals of working age. Thirdly, since psychological well-being was to be viewed as a separate variable, the measure chosen would not include an item designed to measure this construct. To meet these three criteria, Chibnall and Tait's (1990) Quality of Life Scale was utilised. The current research therefore used their definition of QoL ('the person's perceived degree of satisfaction with key psychosocial life areas' p. 284).

Since the concept of QoL as defined by WHO (1995) is culturally bound, studies on QoL in Parkinson's need to reflect this. The author only found one published Australian study on Parkinson's and QoL (McCabe, Firth, & O'Connor, 2009) and, since this was undertaken in the context of other progressive, neurological conditions, the numbers of PWP were limited and effective statistical analysis not possible. The following sections of this chapter therefore review international studies that have

attempted to identify what it is that contributes to QoL in PWP. Despite the differing cultural context experienced by Australians with Parkinson's, and the methodological issues referred to earlier, this research is considered to have some cross-cultural relevance to the current study.

2.3 Parkinson's progression and QoL

The QoL of a PWP deteriorates as the disease progresses (Koplas et al., 1999; Kuopio et al., 2000; Schrag et al., 2000; Slawek et al., 2005). Progression of the condition is generally measured using the Hoehn and Yahr scale that categorises the level of physical disability as rated by a medical clinician according to five stages (Hoehn & Yahr, 1967). At the first stage physical symptoms are confined to one side of the body and have no impact on usual function. At the second stage symptoms become bilateral but there is no impairment to balance. At the third stage PWP are still able to live independently but have a moderate impairment to their posture and righting reflexes. The fourth stage is reached when a patient is severely disabled but can walk and stand without assistance. At the fifth and final stage PWP will be confined to a wheelchair or bed. It is clear that this method of assessing the severity of the illness does not account for many of the functional characteristics of Parkinson's therefore severity may not necessarily be the main influence on QoL.

Behari, Srivastava, and Randey (2005) found that PWP who were medicating with a higher level of levodopa had worse QoL than those on lower doses. This would indicate that the progression of the disease, necessitating higher levels of medication, is related to lower levels of QoL. This may also imply that the gains in QoL for those remaining in employment may be offset by the negative effect on QoL resulting from the elevated levels of medication required to reduce symptoms for the purposes of work. However, this particular study found no significant relationship between the Hoehn and Yahr staging and QoL. In contrast, Schrag (2006) found a moderate association between the progression of the disease and QoL and the majority of research indicates that the QoL of PWP decreases as the condition progresses (Behari et al., 2005; Den Ousden, Van Heck, & De Vries, 2007; Koplas et al., 1999; Reuther et al., 2007).

2.4 Parkinson's duration and QoL

There is general consensus that QoL is not affected by the length of time that a person has lived with Parkinson's, except when duration is correlated with advanced

symptoms (Behari et al., 2005; Kuopio et al., 2000; Schrag, 2006). This finding can be explained in several ways. Firstly, the uncertain progression of Parkinson's means that each individual will be restricted in their daily activities at a different rate. Secondly, the profound psychosocial impact of Parkinson's may depend on previously established social support, psychological disposition and personality rather than a simplistic assessment of the duration of the diagnosis. Thirdly, the effect of the duration of Parkinson's may be different for a younger cohort of people in employment who are endeavouring to fulfil family and social expectations compared to an older cohort who may have different expectations.

2.5 Parkinson's, age and QoL

Age has no significant effect on most aspects of QoL of PWP, with the exception of its impact on the physical dimension of people's lives, with older people with the condition reporting worse physical limitations than younger people (Schrag et al., 2000). This is in contrast to the general population who have been found to experience a worse QoL as they get older. However, Schrag et al.'s study was conducted comparing a sample of PWP and age-matched participants with a mean age of 73. Results may differ if a similar study was conducted focusing on a population of younger PWP.

Behari et al. (2005) found that older PWP had better QoL in terms of emotional function than younger PWP but that there were no significant differences in terms of symptoms or social function. This could perhaps be explained by lower expectations of life of the older participants in this study.

2.6 Parkinson's, gender and QoL

There is no conclusive evidence that gender has an effect on the impact of Parkinson's on QoL. Schrag et al. (2000) found no difference between a sample of men and women with an average age of 73 years, in the degree that Parkinson's has an impact of QoL. In contrast, Behari et al. (2005) found that QoL for women in India with Parkinson's was worse than that of men, however, the average age of their sample was 57 years. Although a younger sample might have produced this alternate finding, it may also be due to some difference in the role expectations between European and Indian women. For comparable medical conditions, Indian men are more likely to seek medical help than Indian women. The sample in this study was recruited from a

movement disorder clinic and it is possible that the QoL of the women had deteriorated much more than that of the men in order for them to seek assistance at the clinic. Nevertheless, a Finnish study, subject to different cultural imperatives, also found that women with Parkinson's experienced a worse QoL than men (Kuopio et al., 2000). Perhaps women are looking after men in order to enhance their QoL but men are not looking after women in the same way.

2.7 Parkinson's, depression and QoL

Depression has been found to be the dominant predictor of a poor QoL although it is not clear whether depression leads to a poor QoL or whether QoL is detrimentally affected by other Parkinson's symptoms and this leads to depression (Behari et al., 2005; Carod-Artal et al., 2008; Cubo et al., 2002; Kuopio et al., 2000; McCate et al., 2009; Reuther et al., 2007; Schrag, 2006; Slawek et al., 2005). Estimates of the rate of depression vary, but studies indicate that approximately 40% of PWP also experience depression (Althaus et al., 2008; Caap-Ahlgren & Dehlin, 2001; Carod-Artal et al., 2008; Cummings & Masterman, 1999; Schrag et al., 2001). The rate of depression is therefore higher amongst PWP than their healthy, age matched counterparts (Schrag et al., 2000). Rates of depression are higher amongst women with Parkinson's than men with Parkinson's (Kuopio et al., 2000).

Despite this high prevalence, depression often goes unrecognised and therefore untreated in PWP. In as many as 65% of cases of comorbidity, neurologists in the USA have failed to make an accurate diagnosis of depression (Shulman et al., 2002). Once diagnosed, the choice of medication to treat depression in PWP is crucial as the combination of pharmacological treatments for primary symptoms and medication specifically for depression may lead to further complications (Althaus et al., 2008; Cummings & Masterman, 1999). Medications for depression in Parkinson's have not been extensively clinically tested and there has been even less investigation of the effectiveness of psychological interventions.

Comorbid depression in Parkinson's does not appear to be directly related to either the severity of a person's symptoms, the age of onset or the length of diagnosis (MacCarthy & Brown, 1989; McQuillen & Licht, 2003; Rao et al., 1992). Instead, depression appears to be related to a person's perception of their condition and how this affects their daily function and ability to participate fully in life. Depression is most commonly seen at the onset of Parkinson's and then again in the later stages of the

condition (Schrag, 2006). The early peak in cases of depression may well be due to a period of adjustment and grief following diagnosis and the later peak due to actual loss of function imposed by progressive symptoms. Loss of employment for those of working age is likely to constitute a significant negative change in terms of a person's financial security and may lead to depression. However, staying in employment under stressful conditions may also precipitate depression in PWP, despite the belief that maintaining work is beneficial.

As with most psychosocial research into Parkinson's, studies with a focus on depression have almost exclusively been conducted with populations with a mean age of at least 60 years. However, rates of depression amongst people with early onset Parkinson's are higher than those with older onset (Schrag et al., 2003). The focus of the current study is on PWP of working age who fall into this younger demographic. They may be faced with not only work related issues, but also elevated levels of relationship and family difficulties and increased stigma due to the effects of Parkinson's that are not common at their life stage (Calne & Kumar, 2008; Calne et al., 2008). Amongst younger PWP there may therefore be more cases of depression experienced as a consequence of the condition and, for the purposes of this research, depression will be viewed as a consequence of the diagnosis. Irrespective of its origin, depression has a significant effect on the QoL of PWP of working age and may have a consequential effect on their employment status.

2.8 Parkinson's, fatigue and QoL

Fatigue is not one of the symptoms used for diagnosis of Parkinson's and yet is repeatedly cited as one of the most debilitating effects of having the disease in terms of QoL (Caap-Ahlgren & Dehlin, 2001; Herlofson & Larsen, 2003; Scaravilli, 2003). In their review of studies on fatigue in Parkinson's, Friedman et al. (2006) found that between 33% and 58% of people with the condition reported suffering from fatigue. Fatigue was not found to correlate with the severity of motor symptoms or to be linked to depression. Although fatigue may contribute to the development of depression in Parkinson's, even when the depression is successfully treated, fatigue can remain (Friedman et al.). Friedman et al. also found that PWP who did not experience sleeplessness or sleep disturbance still suffered from fatigue during the daytime. The existence of fatigue independent of depression and sleeplessness lead Arnulf et al.

(2002) and Herlofson and Larsen to suggest that fatigue was not a consequence of having Parkinson's but due to the pathology of Parkinson's itself.

However, according to Korczyn (2006), the management of sleep problems at night and fatigue during the day in PWP is interrelated. Korczyn attributed night-time sleep problems to difficulties turning in bed, effects of medication and a reduction in motor function leading to less need for physical regeneration and difficulties falling asleep. If these issues were addressed better sleep would be achieved and there would be a consequential reduction of fatigue during the day.

2.9 Parkinson's, perceived control and QoL

As has been outlined above, demographic and illness severity measures have been found to only explain some of the variation in QoL. This has led researchers to conclude that there may be personality related factors that influence QoL when living with Parkinson's but little focus has been given to this area. Koplak et al. (1999) found that perceived mastery was significantly related to PWP's QoL. Koplak defined perceived mastery as a person's belief that they have some control over their illness and its effects. The concept was measured using a scale that reflects an individual's belief in their being able to have an influence over the events in their life and their general life situation. Koplak's finding is supported by evidence that maintaining a sense of independence contributes to the QoL of PWP (Behari et al., 2005).

The progression of Parkinson's is uncertain and this means that certain aspects of the condition are out of an individual's control. Nevertheless, there are some aspects of the condition over which an individual may perceive they do have control, such as making informed decisions with regard to medication and deciding how to address the functional limitations that Parkinson's imposes. Decisions in relation to adjustments to employment due to Parkinson's may constitute an important component of perceived control for a PWP who is of working age and have a significant impact on QoL.

2.10 Parkinson's, physical activity and QoL

Physical activity is beneficial for the QoL of PWP (Baatile et al., 2000; Rodrigues de Paula et al., 2006). Exercise has been found to break the cycle of immobility whereby individuals cease daily activities due to difficulties in accomplishing them. This cessation of activity then makes it harder to undertake physically demanding tasks due to increased weakness and stiffness in muscles

involved. Exercise not only affects the physical domain of QoL of PWP but also has benefits for the psychological domain.

In relation to employment, exercise in the form of mobility and strength work obviously forms a component of jobs involving manual labour. This type of work would therefore appear to have benefits in terms of QoL for PWP. There may be little that at face value constitutes exercise in the majority of non-manual jobs but all jobs involve mobility in order to travel to work and move around once there. Work may also provide a social environment that leads to more formal forms of exercise.

However, it could be that the physical demands of work have a negative influence on QoL if an individual is no longer able to meet the physical requirements of a job. They may lose confidence in their ability to perform certain tasks and be overly fatigued by excessive physical demands resulting in diminished QoL.

2.11 Summary

Depression appears to be the predominant influence on the QoL of PWP. Less research has been conducted on the effects of fatigue but the prevalence of fatigue in PWP indicates that this also has a substantial influence on QoL. Evidence is less conclusive with regard to the effects of the duration and progression of Parkinson's on QoL but the potential influence of these factors cannot be ignored. With a younger, working cohort, the scant findings in relation to perceived control are also of note given that the expectation is that people of working age will normally experience a level of independence and control over their lives.

None of the research outlined above has been conducted in a work context and, with the mean age of all the research samples being somewhere over 60 years, employment has not even featured in demographic descriptions of some studies. Indeed, for many of the older participants in these studies work is no longer of concern. Attention is now therefore turned to research focusing on a working population in order to view QoL of PWP in the context of employment.

CHAPTER THREE

PARKINSON'S, EMPLOYMENT AND QOL

Employment has been found to be beneficial for PWP in terms of its effect on QoL (Klepac et al., 2008). In the only quantitative study investigating QoL that incorporates the influence of work, Klepac et al. found that employed Croatians with Parkinson's scored significantly higher on a measure of Parkinson's related QoL than those that were not working. It should be noted, however, that out of their research sample of 124 men and women, the mean age was 60.4 years and only 25 were employed. A sample with a larger proportion of workers and a younger cohort (not as close to the retirement age) may produce different results. In the absence of further research investigating this positive effect, Klepac's findings need to be substantiated by reference to the literature on other chronic illnesses, employment and QoL.

3.1 Chronic illness, employment and QOL

Employment, whether it is full or part-time, has consistently been found to benefit the QoL of people living with chronic illness who are of working age (see Table 2).

Table 2.

Studies examining the relationship between Chronic Illness, Employment and QoL

Author and date	Chronic condition	Subject characteristics	Measure of QoL/HRQoL	Study conclusions
Koch, Rumrill, Roessler, & Fitzgerald (2001)	Multiple Sclerosis (MS)	227 people with MS, predominantly women (Age M = 47, SD = 11.7), USA	The Quality of Life Scale (Chibnall & Tait, 1990)	QoL is positively related to employment status.
Blalock, McDaniel, & Farber (2002)	Acquired Immune Deficiency Syndrome - Human Immunodeficiency virus (HIV-AIDS)	200 HIV-seropositive outpatients at HIV/AIDS clinic (median age=40, 75% male)	Medical Outcomes Study (MOS), (Tarlov et al., 1989)	After controlling for illness severity, employed subjects reported significantly higher overall QoL than those who were not working.

Table 2. *Studies examining the relationship between Chronic Illness, Employment and QoL (Continued).*

Author and date	Chronic condition	Subject characteristics	Measure of QoL/HRQoL	Study conclusions
Orbon et al. (2005)	Chronic Obstructive Pulmonary Disease (COPD)	210 patients with COPD (Age: M=53.9, SD=6.8) recruited from Dutch general practice	Chronic Respiratory Disease Questionnaire (Guyatt et al., 1987a)	Patients 'disabled for work' had worse QoL compared with 'paid workers'. There was no significant difference between paid and non-paid workers.
Fleer et al. (2006)	Testicular cancer survivors (TCSs)	354 Dutch survivors. All male Age M = 44	Dutch version of RAND-36 (Hays, Sherbourne & Mazel, 1993)	Only small differences between QoL of TCSs and general population. Unemployment and chronic disease combined were greatest predictor of impaired functioning.
Miller & Dishorn (2006)	Multiple sclerosis	215 MS outpatients at MS treatment centre in Israel (Aged 18-60)	SF-36 (Hays, Sherbourne, & Mazel, 1993) MS-QOL-54 (Vickrey et al., 1995)	Employed people with MS had higher QoL and were more affected by physical disability than those not working. Women appeared to cope better with disability than men.

Table 2. *Studies examining the relationship between Chronic Illness, Employment and QoL (Continued).*

Author and date	Chronic condition	Subject characteristics	Measure of QoL/HRQoL	Study conclusions
Dodel et al. (2007)	Narcolepsy	75 German patients, 46 male (Age M = 45), 29 female (Age M = 51)	SF-36 (Hays, Sherbourne, & Mazel, 1993) Euroqol (EQ-5D) (EuroQol Group, 1990)	Those in employment had significantly better HRQoL than those not working, independent of household income and social status.
Heider et al. (2007)	Post lumbar disc surgery	189 German post-operative patients assessed at baseline, 1-4 days post operatively, 2 months and 6 months	WHO-QOL-BREF (Angermeyer, Kilian, & Matschinger (2000)	Patient QoL was consistently lower than general population and was associated with unemployment, part-time employment and inability to retire early.

Table 2 *Studies examining the relationship between Chronic Illness, Employment and QoL (Continued).*

Author and date	Chronic condition	Subject characteristics	Measure of QoL/HRQoL	Study conclusions
Aberg et al. (2009)	Post liver transplant	353 Finnish liver transplant patients. Age M = 55 , 58% female	15D instrument (Sintonen, 2001) which measures non disease specific	Patients working had significantly higher HRQoL than those not working and lower than general population. The lowest HRQoL was amongst those who had retired early.
Patti et al. (2007)	Relapsing-remitting Multiple sclerosis (RRMS)	648 RRMS patients attending Italian MS centres (70% female, 68% < 40 years)	MS-QOL-54 (Vickrey et al., 1995)	Employed patients scored significantly higher than other patient groups in the majority of MSQoL-54 domains. Those with higher levels of education experienced higher HRQoL.

As can be seen from Table 2, for people living with chronic conditions, the relationship between employment and an elevated level of QoL is consistent, despite different scales used to measure QoL, differing gender bias in the research samples and numerous international settings. The majority of scales used in these studies were health related QoL scales or scales specifically designed to measure QoL in a particular population. Such scales are designed to incorporate items relevant to the experience of living with a specific condition. The use of disease-specific scales makes comparisons between results and levels of QoL difficult but does not negate from the overriding significance of employment as a predictor of QoL amongst the chronically ill.

In relation to gender, HIV/AIDS samples are predominantly male (Blalock, McDaniel, & Farber, 2002) whereas MS samples are predominantly female (Rumrill, Roessler, & Fitzgerald, 2004). Furthermore, all testicular cancer survivors are necessarily male (Fleer et al., 2006). All three populations have been found to benefit from employment in terms of QoL. It would seem that employment is equally important for men and women in influencing QoL although this is likely to reflect the cultural norms of the countries in which the research was undertaken. Equal opportunities in terms of education and employment in Australia mean that both Australian men and women have valued positions in the workforce (Australian Bureau of Statistics, 2007).

The studies included in Table 2 also provide several peripheral findings that may be relevant to the current research. There is evidence that the positive effect of employment on QoL is independent of the severity of an individual's condition. Whilst exploring the relationship between employment and QoL in people with HIV-AIDS, Blalock et al. (2002) controlled for disease severity and still found that those employed reported significantly better QoL than those that were not working. This counters the argument that severe symptoms are responsible for both a low QoL and for preventing an individual from participating in the workforce.

The studies outlined in Table 4 also provide evidence that the benefits of employment are not a simple matter of being able to earn income. In people with Chronic Obstructive Pulmonary Disease (COPD) there was no significant difference in the experience of QoL between being paid for work and unpaid employment (Orbon et al., 2005). Similarly, the positive effect of employment in people with narcolepsy is independent of household income or social status (Dodel et al., 2007). As well as generating income, work provides a daily structure to people's lives, the opportunity for

social interaction, a sense of purpose and identity and enforces regular mental and physical activity, all of which enhance an individual's well being (Merz, Bricout, & Koch, 2001), and benefit their QoL.

In people who had successfully undergone a liver transplant, the lowest QoL was found in people who had retired early (Aberg et al., 2009). Early retirement for someone with a chronic condition may have been forced upon them due to health reasons. An individual is therefore likely to lose QoL from no longer participating in the workforce, and also from not being able to exert control over the events that led to this situation. Since perceived control is also related to QoL, the combined effects of forced early retirement are likely to have an adverse outcome in terms of well-being for the individual concerned. Alternatively, with a progressive condition such as Parkinson's, some people may choose to retire early in order to fulfil retirement dreams before the progression of the condition prevents them from doing so.

As can be seen from Table 2, the research that exists in this area is largely confined to illnesses with an onset most commonly during working years (e.g., MS and HIV/AIDS), or conditions that are not age associated (e.g., recovery after back surgery). There are several reasons for this. Firstly, and most importantly, these conditions are seen as interfering with normal mid-life stages such as establishing or maintaining a career and therefore demand research aimed at addressing the impact of the condition on employment. Secondly, in relation to the progression of MS, it is often interrupted by periods of remission and during these times people with MS may find themselves actively campaigning to promote awareness and research in relation to their condition. Finally, in relation to HIV/AIDS, a motivated minority lobby group exists campaigning for gay rights and recognition including work conditions for people living with HIV/AIDS.

Less emphasis is given to issues relating to employment in Parkinson's research, since the average age of onset is 60 years, a stage of life considered to be around retirement age and therefore perhaps not associated with a focus on working life. Furthermore, PWP do not experience remission, nor do they come from a predefined community. They are therefore less well positioned to advocate for improvements in their conditions at work. Findings in relation to the effect of employment status on QoL for people with other chronic diseases are therefore important in directing psychosocial research into QoL of PWP who are of working age. MS and Parkinson's, for example,

share a neurological basis and have been found to have a similar impact on an individual's QoL (Riazi et al., 2003).

The research presented above establishing the benefits of employment for people with chronic illness, substantiates the finding that employment is also beneficial in terms of QoL for people of working age living with Parkinson's. The current study is based on this assumption and endeavours to produce findings that might assist PWP to remain in the workplace should they wish to do so.

3.2 Factors influencing employment of PWP and other chronic illnesses

There is minimal research addressing employment issues for PWP. It is therefore necessary to gain additional insight by evaluating the literature pertaining to factors that have been found to influence the employment experience of people with other chronic illnesses such as MS.

3.2.1 *Disease severity*

As outlined in an earlier section on Parkinson's and employment, PWP report the severity of physical symptoms associated with their diagnosis as being one of the reasons for ceasing employment (Banks & Lawrence, 2006; Martikainen et al., 2006; Zesiewicz et al., 2007). This is consistent with the experience of people with MS. Those with MS who have persistent and more severe symptoms or cognitive limitations caused by their condition are less likely to be in employment than people with MS whose symptoms are less severe, are in remission or are not affected cognitively (Rumrill et al., 2004).

3.2.2 *Physical limitations*

The role of physical limitations in determining employment has not been investigated in Parkinson's as a construct independent of disease severity. However, people managing chronic conditions in the workplace have identified limitations in motor function as the factor that most interferes with an ability to access or maintain employment (Baanders, Rijken, & Peters, 2002). This finding is independent of age, education or gender. However, Baanders et al. found that, after also controlling for physical disability, fewer people between the ages of 18 and 65 in the Netherlands were working than were unemployed. This finding indicates that, although physical

restrictions may be influential in preventing people of working age from participating in paid employment, other factors may be involved.

Although the degree of physical limitations would seem to have an obvious effect on the workplace experience of PWP, there is no evidence that its influence is predominant in relation to other factors. This may in part be explained by employers' willingness to accommodate physical difficulties but apparent resistance to addressing psychosocial issues (Robinson, 2000).

3.2.3 *Depression*

Depression appears to play a role in influencing employment status in PWP (Zesiewicz et al., 2007) although few people made mention of depression in Banks and Laurence's (2006) qualitative study investigating the factors that lead to cessation of employment. In McCabe et al.'s (2008) Australian study of changes to employment status due to progressive, neurological conditions, depression was cited as one of the consequences of leaving employment but not a reason for departure. Since the role of depression is not clear, reference to the influence of depression on employment status of people with other chronic conditions is useful to instruct the current study.

Munir et al. (2005) found that depression was more influential than physical limitations in determining a person with chronic illness' ability to cope with the physical demands of a job. This finding would seem to be consistent with evidence that shows that PWP are more negatively affected by the psychosocial consequences of living with the condition than by its physical symptoms (Carod-Artal et al., 2008; Cubo et al., 2002; Frazier, 2000; Schrag et al., 2000; Schreurs, De Ridder, & Bensing, 2000). Even if depression is one of the factors leading to loss of employment, it may be that other factors are more influential and that depression plays a greater role as a consequence of that loss.

3.2.4 *Fatigue*

The experience of fatigue has been found to be one of the reasons why many PWP decide to leave employment (Banks & Lawrence, 2006; McCabe et al., 2008; Zesiewica et al., 2007). In a sample of 68 patients with a mean age of 58, Zesiewicz et al. found that 49% of PWP cited fatigue as the primary reason for having left their jobs. This is consistent with research into the effects of narcolepsy that has been found to account for 43% of those with the condition leaving work (Dodel et al., 2007).

Fatigue as a generic symptom of chronic illnesses has a more significant influence on work participation rates than disease specific symptoms (Lee et al., 2008; Munir et al., 2005). Individuals with sleep related problems accompanying chronic conditions are half as likely to work as those without such difficulties (Manoccia, Keller, & Ware, 2001) and sleeplessness due to chronic pain is one of the principal predictors of a person's inability to work (Lillefjell, Krokstad, & Espnes, 2006). Irrespective of the specificity of their chronic illness, Baanders et al. (2002) found that people not working experienced significantly more fatigue than those who remained in the workforce. It can be assumed that their level of fatigue may have played at least some part in their decision to leave employment and was more related to their illness than to their employment itself.

Despite the inconclusive evidence as to the reasons for the predominance of fatigue in PWP, its negative influence on a person's ability to remain in employment is clear. Fatigue affects a person's ability to concentrate on the task at hand and its consequences may be fatal when driving or using machinery. It seems likely that the experience of fatigue in the workplace plays a part in influencing the job satisfaction and overall QoL of PWP.

3.2.5 *Level of education*

The role that PWP's education plays in determining employment status has not been investigated. However, a model of vocational rehabilitation-related predictors has been suggested for MS whereby employment and a higher level of education predict a higher level of QoL (Rumrill, Roessler, & Fitzgerald, 2004). According to this model, the number and persistence of symptoms and a high level of stress predict a lower level of QoL. Rumrill et al.'s model explained 42.9% of the variance in QoL in people with MS but, to the author's knowledge, has not been tested with other chronically ill populations. It follows that people with MS who are better educated are more likely to be in employment than those who have less education.

The influence of educational level on employment status may be due to the less physically demanding nature of professional occupations. It may be easier for someone with MS to continue in a professional role than for someone to continue working in a role that is dependent upon physical abilities, although a better paid is likely to mean more financial resources with which to retire early. Results are inconsistent in the predictive value of type of work on employment status in PWP (Martikainen et al.,

2006; Schrag & Banks, 2006). Martikainen et al. found that amongst Finnish workers with Parkinson's, there was no significant difference in terms of maintaining employment between those that were self-employed and those that were salaried, but that those in white-collar type work were more likely to stay working longer than those whose jobs were classified as manual labour. In contrast, Schrag and Banks found that in the UK the length of time that PWP remained in employment following diagnosis was not significantly influenced by type of work or form of employment. Results may not therefore be unquestionably transferred from research into MS to a Parkinson's population.

3.2.6 *Cognitive Function*

The influence of disease severity would necessarily include the role of cognitive function in determining the employment status of PWP (Zesiewicz et al., 2007). PWP have reported difficulties with concentration and memory as contributing to cessation of employment. With reference to the literature relating to employment and chronic illness in general, limitations in cognitive function are one of the work related factors that leads to unemployment (Lillefjell et al., 2006; Roessler et al., 2001; Roessler, Rumrill, & Fitzgerald, 2004). A study in the Netherlands investigating the profile of the chronically ill in the workplace found that after controlling for socio-demographic variables normally associated with unemployment (age, gender and education), cognitive difficulties were significantly associated with loss of work (Baanderset al., 2002).

It is evident that, from an employer's perspective, if an individual is not able to concentrate sufficiently or experiences deficits in their organisational abilities they become a liability in terms of safety, efficiency and productivity. From the point of view of the chronically ill employee, the realisation that tasks are becoming difficult because of cognitive problems is likely to increase work related stress that may be associated with a loss of self-confidence and lead to them withdrawing from the workforce. In all situations of loss of cognitive function, adjustments are necessary to maintain employment. Such adjustments in relation to cognitive difficulties are more likely to occur if the employee concerned tells their employer that they are managing a chronic condition (Munir et al., 2005). Without such disclosure there is likely to be little tolerance for an employee's cognitive limitations.

Since QoL in PWP is associated with cognitive impairment (Klepac et al., 2008; Kuopio et al., 2000) it is likely that the impact of difficulties in meeting cognitive demands at work play a significant role in affecting work related QoL.

3.2.7 *Employers*

As outlined earlier, the majority of UK employers are receptive to making changes at work for employees with Parkinson's if they are provided with information about the condition and its impact (Banks & Lawrence, 2006). This finding concurs with evidence from research into the role of employers in maintaining employment for individuals with other chronic conditions. The role of an employer appears to be pivotal in order for a person with a chronic illness to access or maintain employment (Gignac, 2005; Koch et al., 2005; Lidal, Huynh, & Biering-Sorensen, 2007; Patel, Greasey, & Watson, 2007; Pryce, Munir, & Haslam, 2007; Roessler et al., 2005; Rumrill, Roessler, & Koch, 1999). Support from an employer comes in the form of non-discriminatory hiring practices and fair treatment in the process of establishing adjustments in order to accommodate the person with the chronic condition.

Certain factors have been found to assist a person with MS in remaining in employment (Roessler & Rumrill, 2003). These are flexible work hours, the location of the workplace, somewhere to rest during the day and proximity to toilets and the workplace exit. Unless a person with MS is fortunate enough to have an employer that provides all this prior to diagnosis, it is likely that these work conditions would only be available if an employer is open to making adjustments for an employee with MS. These types of adjustments would directly alleviate the very problems caused by the physical symptoms and cognitive limitations found to be related to cessation of employment.

Other factors that have emerged as significant in assisting people with MS in the workplace are (1) support received from employers in terms of non-discriminatory practice, (2) support in terms of programs to assist their employment, and (3) external supports such as transport (Roessler et al., 2005). Roessler et al. also found that people with MS were concerned about their access to health care and prescriptions.

In a qualitative study of the work experience of individuals experiencing chronic pain, Patel et al. (2007) found that employers were generally viewed as ignorant about the impact of non-visible work impairments and more understanding if there was some physical aid was used to signpost their condition. This supports Robinson's (2000)

finding that employers generally have a narrow perception of what constitutes disability and tend to focus on visible, physical problems rather than less obvious psychosocial issues. An employer's ability to address an employee's psychosocial difficulties is likely to be dependent on the employee's disclosure of such problems. Likewise, there are other factors that influence the likelihood of an employer being open to making adjustments to accommodate a person with a chronic illness experiencing difficulties in the workplace.

In a study of allegations of discrimination against their employers made by people with MS, Roessler et al. (2007) found that claims were more successful in cases where jobs were primarily physical in nature rather than sedentary. This finding confirms that of Robinson (2000). Roessler's study also found that men were more successful in court than women, and younger claimants, those in their 30s, were more successful than older ones, those in their 40s. Of the 3,669 cases examined in their study, 71% were dismissed, highlighting the difference between what is regarded by US law as actual discrimination as opposed to what is perceived to be discrimination by the person with MS.

These figures concur with the finding that cancer survivors recommence work more successfully following treatment if they are involved in a return to work meeting with their employers (Pryce et al., 2007). Pryce et al. found that advances in treatment of cancer have meant that a return to work is often interpreted as a resumption of normal health. Unless an employee explains to their employer how cancer-related residual difficulties might affect their work, the employer may be oblivious to such difficulties and therefore fail to address them. Similarly, amongst workers with arthritis, discussions with an employer have been found to result in more accommodations being made and the employee having a more positive view of employment (Gignac, 2005). Open communication with an employer therefore seems to be essential if both visible and non-visible issues are to be addressed.

Employers appear willing to make the adjustments necessary in order to accommodate employees with a disability if they are educated sufficiently in what may be required and in the legalities of non-discriminatory employment (Jackson, Furnham, & Willen, 2000). In fact, some employers have been found to make it their business to find out about the chronic illness in order to be in a position to best support their staff (Rumrill & Hennessey, 2001). Jackson et al. found that out of a sample of 200 UK employers, over half of them were willing to pay for an applicant with a disability to

attend an interview. These employers were also found to be willing to discuss any illness-related work difficulties at interview and, if testing was required as part of the assessment process, they were willing to allow for extra time and breaks during the period of testing. The determinant of their willingness to make such adjustments was the cost and convenience of providing such accommodation. If it was likely to be expensive or cause inconvenience, employers were less willing to be accommodating. This would suggest that financial incentives could mean that more employers would employ and continue employing people with disabilities. However, studies into the success of financial incentives to UK employers who accommodate people with disabilities have been inconclusive as to their effectiveness (Bambra, Whitehead, & Hamilton, 2005). It appears that at times it is the attitude of an employer that acts as a barrier to satisfactory employment situations for people with disabilities.

Although only some of the literature referred to above related directly to the role of the employer in access to employment for PWP, it is likely that their experience would have many parallels with people with other disabilities. Indeed, there are several reasons that may lead to the conclusion that it might be worse. Firstly, older people with MS appear to be less successful in claiming compensation for discrimination than younger ones, a finding that does not bode well for PWP who are generally diagnosed at an older age than people with MS. Secondly, the fact that employers are more responsive to physical disability than they are to psychosocial disability is also not encouraging for PWP given that the psychosocial consequences of the condition are perceived to be more disabling than the physical ones (Abudi et al., 1997; Brod, Mendelsohn, & Roberts, 1998; Cubo et al., 2002; Frazier, 2000; Jenkinson et al., 1995; Schrag et al., 2000; Schreurs, De Ridder & Bensing, 2000; Suzukamo et al., 2006). In conclusion, it would seem that there is a need for research that focuses on substantiating the influence of perceived social support from employers in relation to access to work for PWP.

3.2.8 *Health providers*

Another significant influence on the ability of a person with a chronic illness or disability to access or maintain employment is the role played by health professionals (Detaille, Haafkens, & Van Dijk, 2003; Johnson et al., 2004; Koch et al., 2005; Pryce et al., 2007; Varekamp & van Dijk, 2006). This relationship has not been the focus of research in relation to Parkinson's.

A common complaint emerging from the literature is that people with chronic illness do not receive sufficient support from their doctors in relation to the impact of their diagnosis on employment. In their study of cancer survivors' adjustment to work, Pryce et al. (2007) found that only half of those surveyed had received any guidance from their general practitioners in relation to concerns about work and that those that did were more likely to return to work. It could be argued that this finding may have been influenced by a sample that was 76% female with an average age of 50 years. These are demographics that may lead doctors to believe that work is not an issue for patients unless it is raised specifically. A qualitative study of female breast cancer survivors also found dissatisfaction with the level of work-related support from doctors (Maunsell et al., 1999). Contradictory to this gender related argument is the finding that men with MS had more complaints about the healthcare they received in relation to work than women (Roessler et al., 2005). It needs to be noted that none of these studies controlled for the importance that participants attached to their work. The role that work plays in a person's life is likely to influence judgements on doctors' support in relation to employment issues.

It is not only general practitioners who have been criticised in relation to support provided to people with chronic illness or disability in work related matters. Johnson et al. (2004) found that people with MS reported that rehabilitation specialists were also perceived as not providing adequate support in helping patients return to work or remain in their jobs. This finding indicates that work is very much 'off the agenda' when health practitioners attend to people with chronic illness.

A recent Australian study investigated the level of satisfaction of the chronically ill with access to healthcare and the patient-centredness of the care they received (Jaysinghe et al., 2008). The researchers found that people who were employed were less satisfied with their access to healthcare than those that were unemployed. Working patients also reported less satisfaction with the patient-centredness of treatment than their non-working counterparts. There could be several explanations for this.

Firstly, in terms of access, it may be that the hours that services are provided are not sufficiently flexible to accommodate workers. Alternatively, problems with access to healthcare may be due to workers' inability to get time off in order to attend appointments. Secondly, it is likely that people who are employed enjoy better health than people that are not working and they are perhaps better equipped to assess what may be lacking from the services they receive and therefore report services to be

inadequate. Thirdly, a lack of person-centredness may be perceived because of the medical profession's limited focus on employment related issues as outlined earlier. Finally, it may be that the medical profession is more focused on diagnosis and medication rather than QoL issues such as employment.

In relation to Parkinson's, an association has been found between patient education about the condition and a patient's overall QoL (Shimbo et al., 2004). Patient education starts with the medical profession who are the first point of contact at diagnosis. PWP are likely to receive less work related support than those with either cancer or MS since Parkinson's is viewed as a condition of the elderly, not of the working population. It is therefore likely that the findings outlined above have direct relevance to PWP.

3.2.9 *Uncertainty about the future*

Robinson's (2000) research into access to employment for people with disabilities found that people with progressive illnesses such as Parkinson's experience particular barriers to employment since they are unable to predict the severity of their disease on a day to day basis, let alone make an assessment as to their needs in six months' or a year's time. The progression of Parkinson's is unpredictable (Duvoisin, 1984; Marjama-Lyons & Koller, 2001; Samii et al., 2004). Therefore there is no way of knowing how PWP will be within the next hour, let alone the next week, month or years. The only certainty is that their condition will become progressively worse.

Uncertainty about future employment has also been found to be a factor related to job stress (Merz, Bricout, & Kock, 2001). Merz et al. concluded that although work can be of enormous psychological benefit to an individual, it can also have negative effects on well-being when physical and psychological complications induce elevated levels of job related stress. Stress is a factor in exacerbating Parkinson's symptoms (Ellgring et al., 1993) and therefore stress produced by uncertainty about work may have a detrimental effect on QoL. MS shares the unpredictable nature of Parkinson's and this unpredictability has been credited with contributing to low levels of self-efficacy in people with MS. The influence of self-efficacy will be discussed in a separate section below.

3.2.10 *Self-efficacy*

Self-efficacy is defined as a person's expectation that they are able to successfully accomplish the things that they set out to do (Bandura, 1986). PWP with high levels of self-efficacy are better at finding support to help them deal with the problems presented by their condition than those with lower levels of self-efficacy (Fujii et al., 1997). Although the direct effect of self-efficacy on employment of PWP has not been investigated, it is logical to presume that self-efficacy would assist in gaining support for Parkinson's related difficulties at work. This presumption is supported by research into self-efficacy and other chronic conditions. In relation to MS, self-efficacy has been established to play a major role in maintaining employment (Roessler & Rumrill, 1994) and in people returning to work after traumatic brain injury, self-efficacy at work has been found to account for 16% of perceived QoL (Tsaousides et al., 2009).

Self-efficacy in people with chronic illness is likely to decrease with a growing awareness of the limitations that the condition causes and the constant uncertainty about what the future holds. Some people living with a chronic illness may have had low self-efficacy prior to the development of symptoms and this characteristic is only likely to become exaggerated post diagnosis. Self-employed people generally have higher levels of self-efficacy and job satisfaction than employed individuals and are perhaps better placed to deal with work-related problems associated with the development of a chronic disease (Bradley & Roberts, 2004). However, as outlined earlier, self-employed PWP have reported being more stressed than individuals employed within organisations where responsibility is shared.

Bandura (1986) suggests that deficits in self-efficacy need to be addressed with interventions that are cognitive, social and behavioural in nature and appropriate to the task at hand. In a work place environment this would mean that a person with a chronic illness such as Parkinson's, would need to learn to identify desired changes to accommodate their condition, to communicate this to employers and involved colleagues, and learn how to take such actions in an effective manner.

Interventions to improve self-confidence and self-efficacy in obtaining accommodations in the workplace are beneficial for people with chronic illness. For a review see Varekamp, Verbeek and van Dijk (2006). This review examined nine studies of various chronic illnesses; none of them included subjects who had Parkinson's.

3.2.11 *Summary*

The factors examined in relation to employment for people with chronic illness including Parkinson's can be divided into two categories. Firstly, there are symptom-related factors such as illness severity, cognitive function, physical limitations and fatigue. Secondly, there are psychosocial factors, in this instance social support from employers and health providers, and psychological factors that relate to personal characteristics of employees such as depression and self-efficacy.

Instinctively there appear to be many aspects of the work experience that are not addressed in the literature on chronic illness and employment. The literature indicates that staying in employment is generally beneficial but this does not account for instances of people choosing to retire early in order to fulfil previously planned retirement dreams before the progression of Parkinson's means they are no longer physically able to do so (Banks & Lawrence, 2006). Furthermore, there is little mention of the impact of support from work colleagues or family and friends, or of a person's diminishing ability to fulfil the demands of a particular job due to the effects of their illness. In fact, with a few exceptions, what emerges from the literature are factors that would seem to be related to all aspects of PWP's lives, not specifically employment. In order to identify work specific factors that may affect a person with a chronic condition such as Parkinson's QoL, recourse to the literature on employment amongst healthy populations is necessary.

CHAPTER FOUR

EMPLOYMENT AND THE JOB STRAIN MODEL

The psychological benefits of employment are well established (Graetz, 1993; Liem & Liem, 1988; Murphy & Athanasou, 1999; Schwingel et al., 2009; Warr, Jackson, & Banks, 1988). Employment is beneficial in terms of financial security and social interaction and, in contrast, unemployment is documented as having a substantial negative effect on a person's life satisfaction.

The beneficial effect of work on people's lives is less clear cut as people approach what is considered to be the normal retirement age (Warr et al., 2004). At this stage of life the choices involved in an individual's work status seem to exert more influence on well-being than work status itself. For example, Warr et al. found that at a later stage in life, the various features of a person's work environment have more influence on the association between employment and well-being than simply whether an individual is employed or not. Warr (2004) established that well-being at older ages is a function of work preferences, as well as some features of the work environment. The relationship between work status and well-being was found to be mediated by personal control, variety, environmental clarity and physical security. There are numerous reasons why these features may also have a heightened relevance to people with chronic conditions such as Parkinson's.

In relation to chronically ill populations, the question of work preference is perhaps more significant than it is for people who enjoy good health. The choice of whether to work or not is often taken away from an individual when the severity of symptoms makes employment impossible. Similarly, when faced with a medical condition that is out of an individual's control, personal control at work may become more important than it was prior to diagnosis.

When people with chronic conditions are still able to choose to work, variety and the environmental features of a workplace may be more critical to them in determining the quality of their work experience than it is to people in good health. If work is not an enjoyable and satisfying experience prior to diagnosis, there is little incentive for a person with a chronic illness to address work-related difficulties brought about by their condition. Finally, physical security at work may be of great relevance to a person living with a condition that entails increasing physical debilitation and

limitations. Each of these features will be explored in the present investigation of Parkinson's, employment and QoL.

4.1 The Job Strain Model

One of the dominant models used to explain the relationship between work and the well-being of employees is the Job Strain Model (JSM) (Karasek et al., 1981), also known as the Job Demand-Control (JDC) model (Van der Doef & Maes, 1999). For the purposes of this current study, the former appellation will be used since the present focus is on reducing strain rather than increasing productivity. The JSM asserts that the principal components required to explain job strain are job demands, job control and social support.

Job strain is defined as the combined effect of a diminished level of general health, experience of exhaustion and depression and a low level of job satisfaction (Karasek, 1979). Job demands are restricted to the psychological demands of a job, comprising workload stressors such as time pressure to accomplish tasks, interpersonal work conflict and the requirement to cope with unexpected problems. Job control is defined as the degree to which an individual has the authority to make decisions about how and when the various components of a job are accomplished. Social support comes in the form of instrumental support (practical assistance from others) and emotional support (assistance in terms of listening to psychological concerns). Both forms of support can emanate from employers, colleagues and friends and family outside the workplace. The JSM is illustrated in Figure 2 below.

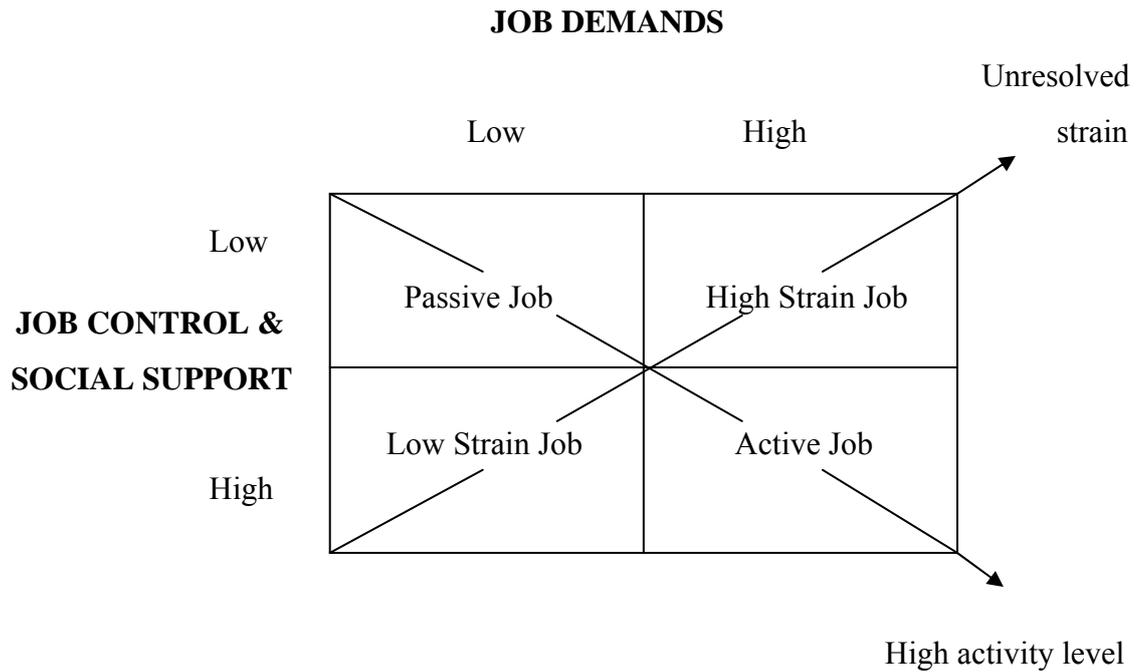


Figure 2. Job strain model (adapted from Karasek, 1979)

As can be seen from Figure 2, according to the JSM, job strain results from roles that involve high demands and low control and social support. Conversely, low strain jobs are characterised by low levels of demand and high levels of job control and social support. Karasek, Triantis, and Chaudhry (1982) stated that employment becomes extremely stressful and potentially harmful to an individual's health when the psychological demands of a job are greater than an individual's control, or decision latitude, over a job and available social support. This assumes an additive effect of job demands, job control and social support and forms the basis of the job strain hypothesis. The JSM asserts that, for an individual to be actively employed and engaged in work that is both motivating and satisfying, high levels of both job demands, job control and social support are required (Karasek et al., 1982). Conversely, jobs that entail a low level of demand, control and social support are categorised as passive jobs, giving employees little motivation or satisfaction.

An alternative model, suggests that the level of job strain results from interactions between job demands and both job control and social support (Van der Doef & Maes, 1999). Job control and social support are seen to moderate the effects of job demands on worker well being. In this way, job control and social support act as a buffer to the effects of job demands. Karesek et al. (1982) found that, in particular,

support from co-workers and supervisors contributed to moderate the effects of job strain. This buffering effect is illustrated in Figure 3.

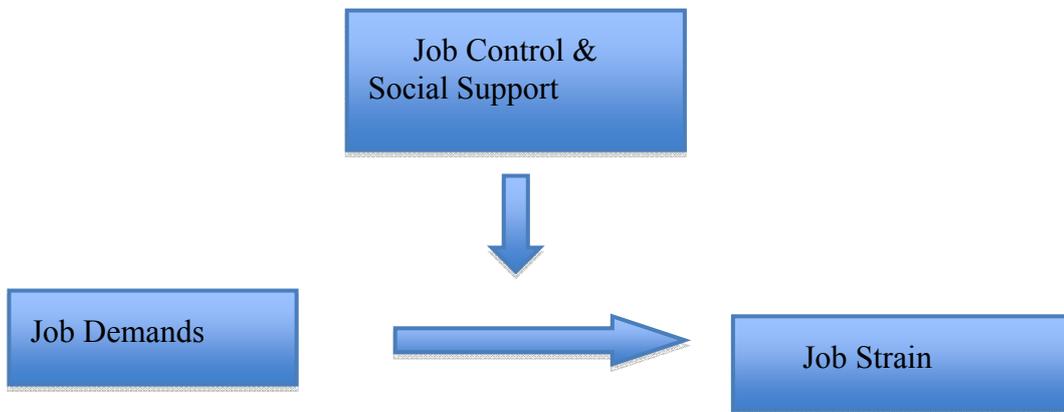


Figure 3. Buffer effects of the Job Strain Model

Studies examining the validity of the JMS have drawn mixed conclusions (De Lange et al., 2003; Kushnir & Melamed, 1991; Shirom et al., 2008; Van der Doef & Maes, 1999; Vanroelen, Levecque, & Louckx, 2009). There is considerable support for the additive effects of job demand, job control and social support but only moderate support for the buffering hypothesis.

One of the problems with the initial additive version JSM is that it assumes that the higher the job demands, the more ‘active’ the job, as long as the job demands do not exceed the level of control and social support. This model is difficult to test, however, as job demands, job control and social support are measured with different scales between which direct comparisons cannot be made. Testing for job control and social support moderating the effects of job demands on job strain does not, however, require these constructs to be measured on comparable scales.

In a review of studies investigating the effectiveness of the JSM, Van der Doef & Maes (1999) concluded that support for the JSM was more likely to be found if measures used were tailored specifically to the characteristics of a particular occupation. In practice this would mean interventions to improve the well being of workers needed to address issues of control and support that were relevant to the demands of a particular job (Sparks & Cooper, 1999). The issue of concept definition in the JSM and how it might apply to a chronically ill population is addressed below.

4.2 The JSM and job demands

As outlined earlier, the original Karasek (1979) model measured job demands in terms of workload stressors such as role overload, role conflict and time pressures. It seems unlikely that the model could be consistently validated using a standardized scale for all types of jobs. For example, a builder's work may be extremely stressful due to the physical demands of the job, particularly as a body's strength decreased with age. In contrast, a social worker's role may involve minimal physical demands but be highly demanding emotionally. The emotional demands of a job have indeed been found to be significant in influencing the well-being of workers and subject to the buffering effects of job control and social support (Taris & Schreurs, 2009). The emotional demands of a job, however, are rarely incorporated when evaluating job demands using the JSM.

In relation to people with chronic illness or disability, it is useful to view adjustments to work in the context of three types of job demands; physical demands, cognitive demands and social demands (Munir et al., 2005). These three categories of job demands correspond generally to the difficulties experienced by people living with a chronic disease such as Parkinson's. For instance, a desk job that has minimal physical demands for a person in good health may become excessively physically demanding for PWP. They may need to climb or descend stairs or walk long distances in order to access their office or attend meetings, a task that may impose substantial physical demands when experiencing physical limitations. Similarly, jobs involving a high level of communication may not be socially demanding to people who are skilled in this area and are in good health. However, following the onset of Parkinson's the same communication task may suddenly become stressful and be perceived as socially demanding.

The above examples demonstrate the need to ensure that job demands are measured appropriately for particular roles or for a particular population. It may be that appropriate measures of job demand would produce more consistent results regarding the buffer hypothesis of the JSM. For PWP it would be useful if the measure included physical, mental and social dimensions. However, including the physical demands of a job may not be appropriate for a model that was initially tested assuming that job demands were psychosocial in nature (Karasek, 1979). Furthermore, as discussed earlier, the psychosocial effects of Parkinson's have been reported to have a greater negative impact on QoL than the physical limitations (Abudi et al., 1997; Brod, Mendelsohn, & Roberts, 1998; Cubo et al., 2002; Frazier, 2000; Jenkinson et al., 1995;

Schrag et al., 2000; Schreurs, De Ridder, & Bensing, 2000; Suzukamo et al., 2006) and perhaps this implies that demands should be restricted to the psychosocial domain.

The psychosocial limitations of Parkinson's present numerous challenges in the workplace, perhaps creating a new dimension of job demands. Adjustments to a role for a person with a diagnosis of a chronic illness may involve an employer or supervisor, with the best of intentions, reducing the demands of a job. Although they may believe that they are making the job easier for their employee with Parkinson's in order for them to maintain employment, the end result may be a job with low demands and also low control. Karasek (1979) described such jobs as passive. Despite an apparent reduction of job strain due to lesser demands, the employee may become disengaged from their role and their workplace and such adjustments may hasten the employee's withdrawal from work. Following the JSM's buffering hypothesis, it would be more beneficial to increase job control and social support rather than decrease job demands in order to reduce job strain. This way the PWP would be more likely to remain engaged with their work. It is clearly imperative that job demands are not viewed in isolation.

4.3 The JSM and job control

Job control is seen either as having a direct effect on well-being or buffering the effects of demands (Sparks & Cooper, 1999; Van der Doef & Maes, 1999; Wallace, 2005). Job control has also been found to buffer the effects of job insecurity and employee health (Schreurs & van Emmerik, 2010). The moderating effect of job control appears to be dependent on the type of job control being appropriate to counteracting the negative effects of particular job demands.

Job control comes in various forms; flexible hours or choice in relation to how or where a task is performed. These factors may be more important to a person living with a chronic illness such as Parkinson's than to their healthy counterparts. For example, an employee who has some control over their work hours is likely to find it easier to attend medical appointments than someone with no flexibility.

Results of studies testing the JSM with healthy populations may not therefore be transferable to PWP who may be a population particularly sensitive to the effect of job control on job strain, regardless of the type of work that they do. An extensive review of the literature suggests that there are currently no studies investigating the role of job control in influencing the experience of PWP in the workplace.

4.4 The JSM and social support

The moderating effect of social support appears to be dependent upon the type of social support that is measured (instrumental or emotional), its source (employer/supervisor, colleagues or family and friends) and how appropriate this support is to meet particular job demands. For instance, support from supervisors and colleagues has been identified as critical to maintaining well being during organisational restructure (Noblet & Rodwell, 2009) and supervisor support has the strongest effect on job strain (Vanroelen et al., 2009). Social support and job control appear to be more beneficial to certain populations, those that are more vulnerable to the negative effects of isolation and lack of control. For example, females in particular were found to be less vulnerable to the effects of insufficient social support in their work than men (Vanroelen et al.).

Also of interest is the source from which social support comes and the effect that this might have on job strain. Support from family has been found to have a different influence to support from co-workers and is different again to support from employers or organisations (Wallace, 2005). For example, support from employers, colleagues and organizations has a buffering effect on job demands. In contrast, instrumental support from spouses has been found to have a direct effect in reducing depression in lawyers whereas their emotional support has a detrimental effect on their well-being. Wallace explained this apparently contradictory finding as resulting from the lawyers responding negatively to emotional support as it highlighted shortcomings in their coping abilities. This last finding challenges the JSM and perhaps highlights the possible deleterious effect of trying to change a difficult work situation through providing emotional support. Social support appears to be only beneficial if it is appropriate to a situation, otherwise it may have an adverse effect.

As a vulnerable population, PWP may be more sensitive to the effects of social support than their healthy colleagues. They may also be recipients of social support that has an adverse effect on well-being. For example, job demands may be simplified in an effort to reduce job strain but result in a job becoming boring or even demeaning. Similarly, well intentioned offers of sympathy may make a PWP feel worse about their condition. The physical presentation of Parkinson's can often be misleading and may result in the needs of a PWP being misinterpreted.

4.5 The JSM and self-efficacy

Evidence of the role of self-efficacy in reducing job strain is inconclusive. Self-efficacy has been found to buffer the effects of high job demands on job strain through its influence on coping skills of people in the workplace (Salanova, Grau, & Martinez, 2005). Furthermore, Jimmieson (2000) and Schaubroeck and Merritt (1997) found that high levels of self-efficacy were influential in increasing employees' control at work. This influence may be culturally bound since the moderating effects of self-efficacy on job control's influence over job strain was found to exist amongst US employees but not similar employees in China, where more individualistic contributions to the working environment may be less acceptable (Nauta, Liu, & Li, 2010). Moreover, an investigation into the role of self-efficacy during times of insecurity at work found that it did not have a significant influence in protecting the health of employees (Schreurs & van Emmerik, 2010).

It makes sense that individuals who have well developed problem solving skills, for example, are more likely to find solutions to increased demands in their work and able to activate appropriate coping skills to prevent the increased perceived job demands from having a detrimental effect on their psychological health. It also seems logical that individuals with high levels of self-efficacy would be able to facilitate more control over their work environment. However, for employees who feel vulnerable at work, whether this is due to impending redundancies or the difficulties of managing a chronic illness such as Parkinson's, self-efficacy itself may be challenged and less effective in managing work related difficulties. Although self-efficacy may be crucial to those working whilst managing chronic health conditions, it may be that the challenges are too great for self-efficacy to be effective. Alternatively, PWP may have high levels of self-efficacy in some areas of their lives e.g. parenting, but may not possess self-efficacy appropriate to solving work related issues.

4.6 Work and individual characteristics contributing to the JSM

The JSM has been successfully tested in Australia, incorporating job specific factors and individuals' employee centred characteristics into the model (Noblet, 2003; Noblet, Graffam, & McWilliams, 2008). In this way the JSM can be tailored to suit specific work situations or specialised populations. This would seem to be an appropriate way of adapting the JSM to PWP. The majority of work in this area has

focussed on individuals undergoing changes to their work environments rather than changes to their health status.

Noblet (2003) used the JSM to examine the work characteristics responsible for promoting job satisfaction and psychological health amongst the staff of a public sector organization in urban Australia. The JSM was extended to incorporate six job-specific stressors previously identified through focus groups. Noblet analysed data using a two-step hierarchical regression, entering the standard variables of the JSM at the first stage. Job control and social support both emerged as significant predictors of psychological health (explaining 73% of the model) and of job satisfaction (explaining 94%). In addition, one of the six additional factors specific to this cohort, 'unrealistic deadlines', explained about a quarter of the variance in psychological well-being.

The results of this research provide very specific targets for interventions to improve the health of employees in a particular workplace. Similarly, employee centred factors have been found to enhance the JSM (Noblet, Rodwell, & McWilliams, 2006). In particular, problem and emotion-based coping appear to play a significant role in predicting work related psychological health.

4.7 The JSM and premature cessation of employment

The JSM has been useful in explaining why some leave the workforce prematurely whilst others remain (Hasselhorn et al., 2008). In some cases a change from a job that evolved from being one of low level of strain into one of high strain resulted in employees being twice as likely to leave the workforce as those that did not undergo this strain. The onset of a chronic illness such as Parkinson's may have a similar effect by turning what was a low strain job into a high strain one, also resulting in employees leaving their job. The JSM may therefore provide a useful framework to investigate the factors involved in PWP maintaining employment.

4.8 The JSM and chronic illness

The JSM has also been tested to assess particular health risks, most predominantly Coronary Heart Disease (CHD) (Aboa-Eboule et al., 2007; Karesek et al., 1981). High strain jobs involving high psychological demands and low levels of control or decision latitude increase the risk of experiencing CHD. Moreover, people experiencing acute coronary syndrome are likely to take longer to return to work if their employment involves high demands and low levels of control (Fukuoka et al., 2009).

High job strain is also associated with an increased incidence of depression (LaMontagne et al., 2008; Mausner-Dorsch & Eaton, 2000; Wang et al., 2009). High job strain is more likely to lead to CHD or depression in people of low socio-economic status than it is in people of higher socio-economic status. These findings provide valuable information on which to design work-based interventions that might reduce the incidence of these two major health conditions.

Both CHD and depression are acknowledged as predominant economic burdens and therefore research has focussed on solutions that might reduce their financial impact (Aboa-Eboule et al., 2007; Karasek et al., 1981; LaMontagne et al., 2008; Mausner-Dorsch & Eaton, 2000). No such attention has been paid to Parkinson's since it is only recently that its impact on the productivity has been assessed. Job strain related research into CHD and depression concentrate on prevention of these conditions. In the case of Parkinson's, the emphasis needs to be on the possible role of job strain in exacerbating the condition and leading to premature withdrawal from the workforce.

Gignac, Sutton, and Badley (2007) developed a scale to measure job strain specifically for people with chronic illness. They found that uncertainty about the future, psychological acceptance of the condition and the balancing of multiple roles were factors identified as contributing to job strain for workers with arthritis. These additional factors were found to be more influential on job strain than work related factors. Such factors could therefore be incorporated into the JSM to make it more specific to a chronically ill population. For example, PWP are likely to experience uncertainty about the future, as well as uncertainty in managing the fluctuations of their condition on a day to day basis. Indeed, uncertainty about the future has been identified as a predictor of job strain in healthy populations (Strazdins et al., 2004). However, other factors relevant to people with arthritis may not transfer so easily to a Parkinson's population. For instance, one of the concerns of people with arthritis is related to the invisibility of their condition. In contrast, PWP report more often being concerned about making their symptoms less obvious. Although Gignac et al.'s (2007) scale informs the current work, it cannot be assumed that it is appropriate to people with neurological conditions such as Parkinson's and will therefore not be used as a measure of job strain in the current study. It does, however, highlight the importance of developing or adapting a model to make it relevant particular populations, in this case, to PWP.

Job strain and job control have been found to have independent effects on insomnia and both control and social support have buffering effects on the relationship

between job strain and insomnia (Nomura et al., 2009). Although there have been inconsistent findings in relation to the buffering hypothesis, perhaps it is particularly relevant to populations living with chronic conditions. Such populations may be more vulnerable to the effects of control and social support. However, there is little published research using the JSM to examine the effect of work related characteristics on people with chronic illness and none with specific reference to Parkinson's.

The principal components of the JSM, job demands, job control and social support may be more salient to PWP than to healthy individuals. Previously met job demands may become an issue as the limitations imposed by Parkinson's make them difficult to meet. The lack of control over a diagnosis of Parkinson's and the unpredictability in the course of its progression may mean that control over other aspects of life, such as work, become increasingly important. This challenging situation may be exacerbated by an unsupportive social milieu. PWP may therefore represent a population that is particularly vulnerable to the effects of demand, control and social support as represented by the JSM.

Although PWP are employed in as broad a spectrum of occupations as healthy workers, they may share specific employee centred characteristics that influence the negative effects of work strain on their psychological health. These employee centred characteristics could be added to the JSM to produce a chronic illness specific model. Such a model could potentially provide a basis for addressing workplace issues for PWP and give them more choice about whether they remain in employment and enjoy the consequential benefits of doing so in terms of QoL.

4.11 Conclusion

The research presented above provides many clues as to what work related factors may be important in influencing PWP's psychological health and QoL, but no conclusive evidence. Parkinson's related QoL research does not adequately account for PWP in the workforce due to its focus on an older demographic. Chronic illness and work related research does not include Parkinson's in its repertoire of relevant conditions and there is little Parkinson's specific material in this area. The buffering effects of job control and social support in the JSM appear to reflect some part of the work experience of people with chronic illness. Absent from this literature review is sufficient knowledge about what might be specific to PWP in the workplace.

There is a body of evidence indicating that staying in the workforce is beneficial for the QoL of PWP. Although there has been some research into the demographic and health related variables that affect PWP's ability to stay in the workforce there is little information available about the psychosocial and work related factors that make continued employment possible and beneficial.

It is clear that certain factors such as depression and fatigue have a significant negative impact on the QoL of PWP. It also seems clear that fatigue and an ability to meet cognitive demands of a job are relevant to the work experience of PWP. These latter associations, however, are not well established. Nor is there quantitative evidence of work related factors being associated with the psychological well-being and QoL of PWP in employment. By identifying these factors, interventions could be structured in order to improve the experience of PWP in the workplace and their associated QoL.

The aim of this current research is to identify work related factors that influence the employment experience and related psychological well-being and QoL for PWP. This objective is to be reached by testing an adapted version of the JSM on a population of PWP who are currently in employment. In the absence of sufficient prior knowledge about the work related concerns of PWP that might be incorporated into the JSM, this study incorporates preliminary scoping interviews in order to establish these. This research was therefore undertaken in two stages. Stage One is a qualitative study aimed at identifying factors that might be added to the JSM in order to make it effective in explaining the work experience of people with Parkinson's. Stage Two is a quantitative study testing the application of the JSM to PWP in the workplace, with the addition of the Parkinson's specific factors identified in the initial qualitative study.

CHAPTER FIVE

STAGE ONE: PRELIMINARY QUALITATIVE STUDY

5.1 Introduction

As outlined previously, there were several reasons for engaging in a preliminary qualitative study in order to develop a valid quantitative questionnaire for examining the application of the JSM to a Parkinson's population. Firstly, there was limited existing Australian research on Parkinson's and employment on which to base a questionnaire investigating work factors of relevance to PWP. Only McCabe et al. (2008) have published research relating to the work experience of PWP in Australia and, as referred to earlier, there are limitations to the application of their results to the focus of the present investigation.

Secondly, a qualitative investigation provides an opportunity for participants to present their own perspective without being limited to pre-ordained aspects of their condition or limiting their experience of Parkinson's to a quantifiable analysis of their symptoms. With reference to Liamputtong, (2009), a variety of methodologies were considered for qualitative data collection and analysis for the current study.

Semi-structured interviews with broad, open questions were chosen in order to allow participants to prioritise their concerns (Liamputtong, 2009). Structured interviews would not have allowed for concerns to emerge from the interviews in order of their own priorities. A second choice needed to be made between using focus groups to collect data as opposed to individual interviews. Although focus groups would be more effective in terms of time and cost for an unfunded project, individual interviews were used as these provided the necessary confidentiality for people to feel able to 'tell it like it is'. The approach used was in accordance with the principles of grounded theory as expounded by Corbin and Strauss (2008). This entails conducting interviews using broad based, open ended questions so that participants are permitted to set the agenda.

Corbin and Strauss' (2008) suggested method of analysis was also followed. This involves making memoranda in relation to the first interview before conducting the second. These memoranda allow identification of emerging themes and the opportunity to confirm findings from the first interview in the second interview by use of probes. Memoranda are made after each interview in order to identify areas that require probing in subsequent interviews. This process continues until all emerging themes have been

validated in subsequent interviews and saturation is reached with no new themes emerging. One of the advantages of Corbin and Strauss' grounded theory approach for analysis is that the researcher can work alone without using other data analysts. Furthermore, once saturation is reached, no more interviews are conducted, hence obviating the need for excessive data collection. This approach is particularly useful when the scope of the research is limited by availability of personnel and funding.

The aim of Stage One of this research, the qualitative study, was to explore the employment experiences of PWP in order to gain a descriptive account of what it is like to work with the condition. Secondly, this stage of the research aimed to ascertain the work-based factors that are perceived to have the greatest influence on psychological well-being and QoL.

5.2. Method

5.2.1 *Participants*

Interviewees were sourced with assistance from Parkinson's Victoria who contacted members of their organisation who were eligible to participate (individuals with a Parkinson's diagnosis who were currently working or had very recently left employment). A total of six participants were interviewed, four male and two female, reflecting approximately the proportion of males and females in the workforce in the general population (Australian Bureau of Statistics (ABS), 2009). Initially it was envisaged that a larger sample would be interviewed. However, since clear themes were emerging and re-emerging repeatedly it was decided that only a small number of interviews were necessary in order to establish the most salient work related factors for PWP.

5.2.2. *Materials*

A copy of the interview is included as Appendix A. Initially questions were asked regarding demographic detail (e.g., age and gender), nature of work (e.g., type of work, hours of work) and diagnosis (e.g., time since diagnosis, presence of symptoms). Then, based on the principles of grounded theory (Corbin & Strauss, 2008), the interview consisted of four questions designed to allow participants to lead the direction of the work related information they provided. The questions were: 1) What type of work do you do?; 2) How has Parkinson's affected your work?; 3) What has made things harder at work since having Parkinson's?; and 4) What has helped you to work

with Parkinson's? Prompts were used to encourage the participants to expand on their responses. Once their spontaneous responses to these four questions were exhausted a series of prompts were used to probe in relation to topics that had not been referred to but had been raised in the literature or in preceding interviews with other participants, e.g. 'so, there were people who supported you' and 'that sounds like it's part of your personality that has helped deal with Parkinson's'.

5.2.3. Procedure

Ethics approval for Stage One was obtained from Swinburne University Human Research Ethics Committee (see Appendix B). Parkinson's Victoria sent letters to ten of their active members who were known to be working, asking if they would be interested volunteering to be interviewed for this project. The letter was composed by Parkinson's Victoria and was not made available to the researchers. Those interested were asked to contact the researcher in order to arrange a suitable time for interview. Responses were received within a week from six PWP. Interviews were scheduled over a period of eight weeks at times and places convenient to the participants, four of them in their own homes and two at the Swinburne Psychology Clinic. Participants were given verbal and written information regarding the study and the interview process before signing informed consent forms (see Appendix C). This included information related to the aims and voluntary nature of the study, participants' right to withdraw at any time and details of avenues for complaint or counselling following participation. All interviews were digitally recorded and lasted between 55 minutes and 100 minutes. Interviews were transcribed by the researcher and details changed where necessary to ensure anonymity of the participants. Participants were also given pseudonyms in order to protect their anonymity. Participants were sent the transcript of their interview and asked to inform the researcher if they wished anything to be changed or deleted (see Appendix D). No changes or deletions were requested. As mentioned in the *participants* section, no further participants were sought since the research decided that the repetition of themes in the initial six interviews indicated predominant themes shared by PWP in employment.

5.3 Analysis

Analysis was conducted in accordance with the principles of grounded theory, as outlined by Corbin and Strauss (2008). This involved listening to the audio of the first interview and reading the transcript several times before undertaking the second interview. Memorandums were made in relation to the first interview in order to ensure that any emerging themes could be identified and explored with prompts where necessary in subsequent interviews. This same process of writing memorandums was used after the second and subsequent interviews in order to consolidate or question what appeared to be the salient emerging themes. The same themes were emerged consistently from each of the six interviews so it was decided that this small sample was sufficient in order to identify variables to inform a questionnaire. This decision was made bearing in mind the restrictions imposed on the analysis of quantitative data when working with a specialised and therefore small population; it was necessary to limit the number of variables to be investigated in order to ensure the effectiveness of analysis. In accordance with grounded theory, only those themes that were raised by participants were deemed to be significant and therefore worthy of inclusion in the quantitative questionnaire.

It should be noted that very few of the planned questions were used in interviews as participants tended to disclose information relevant to the research in response to initial questions relating to nature of their employment. Although information that was provided following prompts elucidated themes, analysis based on grounded theory requires that themes need necessarily to have been established by the participant rather than by the researcher (Corbin & Strauss, 2008).

5.4 Results

The four male and two female participants ranged in age from 48 to 58 years ($M = 53.80$ years). Two participants described themselves as employed full-time (one self-employed), two as employed part-time, one self-described as semi-retired and self-employed and the sixth participant had left the workforce within the last six months and was working part-time on a voluntary basis. They had a range of occupations, professional, semi-professional and trade and differing levels of responsibility during their working lives. All participants had changed roles since diagnosis. The time since diagnosis ranged between 1.5 and 6 years ($M = 1.67$) and the time since first symptoms were noticed ranged between 6 and 16 years ($M = 10.50$).

Five main themes emerged from the analysis of data. The themes were fatigue, demands of the job, control, social support and self-efficacy. There were also several sub-themes that will be discussed below. But first, a summary of the reasons participants gave for wanting to work provides support for the premise of this study, that remaining in employment is beneficial for PWP should they wish to do so.

5.4.1 Benefits of employment

All participants were in no doubt that staying at work was beneficial for their psychological health as long as they were physically and mentally able to do so. Work was described as providing mental stimulation and social contact as well as helping PWP to maintain a purpose in life that was crucial to psychological well-being.

Ed: *“I know I’m a whole lot better off while I’m at work ... While you are work you are keeping busy so work means a lot, it’s very important.”*

Neil: *“It keeps a bit of social contact and keeps my mind ticking over as well.”*

Bill: *“With the business that I have it’s so important to me that I can do something constructively ... I do it because it makes me feel good ... I derive a lot of satisfaction from it.”*

The acknowledgment of the important role that work plays in a person’s life appeared of particular value when faced with the decision of leaving work or finding some way of adapting a role so that it could accommodate Parkinson’s.

Anna: *“I had decided I would rather be there for the long haul and be part of the fabric rather than say I was going to leave and really have nothing to go to. It gives me a reason to get up.”*

The one participant who had fully left employment had done so because she accepted that she was no longer able to cope with its demands or make changes that would make this possible. However, acknowledging the important role that work had played in her life she had substituted paid work for small amounts of voluntary work to give her job satisfaction and provide benefits to her quality of life.

5.4.2. *Job Demands*

Participants referred to the demands of their employment in two different ways. Job Demands were described as either ‘excessive’ or ‘appropriate’ and seemed to fall into two main categories, those that are physically demanding and those that are cognitively demanding. The demands of a job were talked about within the first few minutes of the interview in all but one case, the exception being the participant whose job demands were viewed as appropriate and well within his physical and cognitive capacities.

Past roles had been abandoned in five out of the six cases because of the excessive physical, cognitive or both physical and cognitive limitations that Parkinson’s imposed on the participant in terms of them meeting the demands of their job.

5.4.2.1 *Physical demands and limitations*

In reference to the primary symptoms of Parkinson’s, participants talked of difficulties in relation to impairments to fine and gross motor abilities and postural stability.

Neil: *“As a classroom teacher you are physically up and down, up and down. You know, you walk miles in the classroom and in the end I found I couldn’t bend over the children as they were working, I couldn’t go behind them and bend over them to mark their work over their shoulder, I’d pitch forward ... and some days I couldn’t even hold a pen.”*

Ed: *“A lot of construction sites are very rough, unsteady, I’d have to do a lot of climbing ... balance is one of the problems with Parkinson’s.”*

Neil: *“Typing had started being a problem, not that I had ever been a proper typist, but I used to be able to do it quite fast using three or four fingers. But now it’s with one finger on my right hand so that really slows it down quite a bit.”*

Participants talked of various ways of overcoming the problems associated with the excessive physical demands of their work in order to remain in their job.

Ed: *“Anything I can’t do I just have to mention it and they’ll get me something else. They tend to leave a lot of the smaller jobs for me now, none of the heavier type of work which makes it a bit easier.”*

Ed also said that he no longer attempted tasks that involved reliance on his ability to balance and Neil had accepted assistance from a colleague to do some of the tasks that involved typing.

5.4.2.2 Cognitive demands and limitations

Consistent with the symptoms of Parkinson’s, not all participants referred to cognitive impairments as having an effect on their work. Those who did described the difficulties they experienced in organising themselves to meet the demands of their job.

Neil: *“I start doing one project and get a bit frustrated and I walk past another one and pick that up and end up having a dozen different jobs going at once and it seems that the concentration just doesn’t last and I get frustrated and switch to something else.”*

Bill: *“At times I forget appointments. I write everything in my diary. If it’s not in the diary it doesn’t happen. But even when it is in the diary sometimes I forget to look at it or I get it wrong... The difficulty is that my memory is not that good so there are times when I make the same mistake two or three times before it sinks in.”*

Cognitive limitations were also cited as causing issues related to punctuality:

Neil: *“It doesn’t seem to matter what I do, I still seem to be that couple of minutes late, I just lose track of time.”*

5.4.3 Fatigue

All participants referred to fatigue as a limitation affecting their ability to effectively fulfil the demands of their work. Three out of the six interviewees referred to fatigue within the first few minutes of the interview.

Ed: *“I was forever stuffed, I was tired of being tired, you know, worn out and always wanting to sleep.”*

Neil: *“At work, if I stop talking I fall asleep, like if I’m in a meeting I’m hopeless, I fall asleep in meetings all the time.”*

Nell: *“I decided that, even doing casual work for one day with colleagues bending over backwards for me, I just physically couldn’t do it. The fatigue was crippling”.*

Rob: *“I couldn’t give the job my full energy any more because I didn’t have the energy to give.”*

In terms of the demands of a job being appropriate to accommodate the level of fatigue experienced by PWP, one participant described what he believed was the perfect job that involved periods of waiting between designated tasks when he was able to have a nap. Two participants said they would take a nap during their lunch break in order to combat fatigue. A third worked from home, allowing him to sleep when necessary and only work when not fatigued. In all three cases the combination of the demands of the job and the symptoms of Parkinson’s may have contributed to causing fatigue. However, in these instances, the nature of the demands of the job was able to accommodate some relief for the fatigue. This was not the case for Nell who had just left employment having been unable to accommodate the high levels of fatigue that she experienced.

5.4.4 Control

Control emerged as a dominant theme most commonly expressed by its absence, either due to the characteristics of Parkinson’s or because of the nature of a job. Control was specifically referred to in the following ways:

5.4.4.1 *Acceptance of a chronic condition*

Participants talked of the difficulty of accepting their diagnosis in terms of losing control over the decisions that governed their lives. By its very nature, chronic illness is neither planned nor planned for, and some participants reported feeling a loss of control in relation to their work, and their lives in general, post-diagnosis.

Nell: *“It (Parkinson’s) just pulls the rug out from under your feet, I felt legless, I suppose.”*

5.4.4.2 *Unpredictability of symptoms*

Parkinson’s symptoms do not manifest in a consistent manner and participants referred to the difficulties that this presented in the work place. Participants reported never knowing how severe symptoms would be on any particular day or at a particular time of day. This means that, for instance, efforts to combat the fatigue that accompanies Parkinson’s by reducing a person’s workload or hours of work may not necessarily be beneficial.

Nell: *“I thought I’d work part-time, two or three days a week and I’d have the other days to recuperate. But the problems weren’t from day to day, it was from within the day. Even if I thought I’d only work half days, some half days were bad and it’s that big unknown, you don’t know what you’re going to be like from one part of the day to the next depending on where you are with your medication.”*

Bill: *“There were good days and bad days. Good days, I could work for hours Other times, I would hardly have to do anything, I’d be cramped up.”*

This unpredictability also appeared to present problems in terms of how others tend to perceive the condition, depending on whether others rated working capacity based on an ‘on’ period or an ‘off’ period.

Ed: *“One of my biggest problems to start with was people were treating me as if I had to be wrapped up in cotton wool when I first got it and they were stopping me from doing things that I still could do but they didn’t want to put me under*

any pressure or strain and I thought, crikey, I can do that, don't stop me now. And that can still be a problem. Because you can't do it one day doesn't mean you can't do it the next, you know. It's a stupid disease, it can vary from day to day."

Neil: *"It varies so much from one day to another so markedly that sometimes people think that you're bunging it on."*

Participants described several ways of regaining control over their work when it was threatened by fluctuating symptoms. One participant, who reported dealing with not only fluctuating symptoms but also fluctuating work demands, described taking medication earlier than scheduled if coming up to an 'off' period when the demands of the job were at a peak. This practice had resulted in the participant being able to competently meet the demands of the job, thereby giving her a sense of control.

Another participant, whose work involved providing a service for individual clients, described how it was only possible to work efficiently for clients who did not have strict or urgent time lines in which they needed work to be completed. By only taking on work that was flexible in terms of completion time, he was able to avoid the sense of loss of control that might be brought about by not being able to meet a deadline. This participant used a telephone answer machine to filter potential clients on the basis that those with urgent time constraints would not wish to wait for a call to be returned. In this way he was able to restrict his client base to those for whom time was of less consequence and would be satisfied by the service that he was able to provide. By working from home, he was also able to control over when he did his work.

Bill: *"Sometimes I could work well into the evening. There were good days and bad days. Good days, I could work for hours ... Other times I would hardly have to do anything and I'd be cramped up. Like yesterday, I slept just about the whole day."*

All participants made reference to the regime of medication enforced by Parkinson's. The overall impression was that participants were controlled by their medication. Only one participant talked about taking control of their medication to suit their needs, as referred to above. It should be noted that this participant worked in a medical field and may have had a high level of self-efficacy with respect to managing medication.

It seemed clear from participants' references to times when they had forgotten to take their medication that without it they would no longer be in employment. However, the medication for Parkinson's is not 'one size fits all'. One participant described the process of starting to take medication after initial diagnosis and how it took some time to stabilize. This period of adaptation to a new medication regime is likely to contribute to exacerbating the accompanying feelings of loss of control when a person receives a Parkinson's diagnosis. This particular participant advocated a period of time around diagnosis when decisions regarding work should be put on hold, as at this time it would be impossible to assess a person's work capacity until the effects of the medication have stabilised.

In another instance, a participant's working life as well as his financial security, were almost destroyed due to the addictive gambling problem that he developed as a side effect to the medication. Clearly, medication can have an impact on control. It seemed that participants felt they became 'slaves' to their medication and felt they had insufficient knowledge about its consequences in terms of initial stabilisation and ensuing side effects.

Nell: *"You're dependent on those tablets to be able to just physically move and do things in general ... I feel like a music box dancer. When I take my medication it kicks in and I go really well. Then I just get slower and slowerAfter your medication you just wait for it and wind up again and it's like that throughout the day."*

5.4.4.4 *Ability to attend medical appointments*

Participants were engaged in employment involving varying daily routines and levels of responsibility and authority. Dependent on the nature of a participant's work they reported differing levels of ability to accommodate Parkinson's related medical appointments. In Nell's case, her need to take time off to access health services

appeared to be one of the factors that led to her leaving her employment not long after diagnosis.

Nell: *“Now my whole life revolves around doctors’ appointments, it’s just too disruptive and I don’t think any workplace in the end can afford to have someone taking off three or four days a month for medical appointments.”*

Ed appeared to share the view that an organisation could not be expected to accommodate continual requests for time off to attend medical appointments and reported experiencing discomfort in having to repeatedly ask permission to do so.

Ed: *“It just gets to the point where you’re sick of asking people for things. It was great that I was able to get time off to see my doctors to go and ask for a half day here and half day there. They do have a business to run.”*

A work schedule involving ‘down time’ was more suitable to accommodating the plethora of medical appointments associated with having Parkinson’s than one where you are required to be ‘on duty’ throughout the day. Similarly, shiftwork, although problematic in some ways, was also reported as allowing PWP to attend medical appointments without having to ask for time off. It was clear that participants who worked part-time or were in higher positions within an organisation were able to arrange time out to attend medical appointments without having to repeatedly seek permission from a superior. Self-employment also allowed for the flexibility to accommodate day-time health service commitments. Thus, PWP have differing levels of the control over their ability to attend medical appointments associated with the condition.

It was evident that some employees exerted more control over their work than others. This was either due to a formally established position including a title and authority within an organization or, less visibly, due to an unspoken acknowledgement of worth to the organisation based on experience or capability. When changes to a role were necessary to accommodate chronic disease, this was accomplished more easily by those who were either in decision making positions or were confident of their value to the organisation that employed them. Rob, for instance, was in a senior management

position and therefore in an easier situation than Ed who was dependent upon a supervisor. The ultimate control at work appeared to be through self-employment.

Bill: *“Now because I’m self-employed I can decide whether I’m going to do something or whether I’m not.”*

5.4.5 Social Support

Other people play an integral role in helping PWP continue to work. As can be seen from previously cited quotes, the support and reaction of others to Parkinson’s was a theme that arose during all interviews. Participants were keen that others did not feel sorry for them but wanted them to have some sort of understanding of their experience of living with Parkinson’s. The role of support was different dependent on who it came from, employers, colleagues or family and friends. Without such support all participants acknowledged that it would not be possible to make the changes necessary in order to continue to work or to get the time off necessary to take care of health needs. Participants reported wanting to remain part of the team and be connected to others through their work but also were in most cases concerned that they were perceived as being able to pull their weight thereby justifying their position within the team. Participants were appreciative of the assistance that others offered with tasks that were no longer possible. In most cases participants viewed those around them as supportive. There were a few salient exceptions where others had not been supportive at all, in fact, quite the opposite.

Anna: *“I did have one of my colleagues, I was really quite surprised at her reaction, she really distanced herself and I found that quite sad.”*

It was apparent that often people’s intentions were well meant but their actions were not necessarily appropriate.

Ed: *“I told my supervisor and he made out as if, “Well, you’re not going to be here for much longer, we won’t tell anyone, we’ll keep it a secret” sort of thing. That*

was his idea, not mine. If any of the big bosses came up to talk to us he would push me aside, encourage them not to talk to me so that they couldn't see that there was a problem."

This particular supervisor may have been acting out of concern for Ed and felt that he was protecting his job, but his actions served to take control of the situation away from Ed thereby damaging his self-esteem. Two participants described situations where they had volunteered for particular tasks and been overlooked with no explanation.

Neil: *"I'll put my hand up for things and they've taken my name down and they basically must have thrown it in the rubbish bin because I never get told."*

Neil explained this phenomenon as being a result of people's difficulty in knowing how to handle the situation. Some colleagues or employers presume that PWP are not able to take on a task and, based on this presumption, make decisions or judgements without consultation. This may leave PWP feeling irrelevant, invisible and with no control over the situation. An action taken by an employer or colleague that was intended to be supportive turns out to have a negative outcome for PWP. The appropriateness of others' actions depends in some part on how much PWP have disclosed to employers and colleagues about their condition and the way it affects their ability to work.

5.4.6 *Disclosure*

Bill told all people that he came into contact with that he had Parkinson's and what that meant. He said that because of this there was never a problem with how people reacted to him or to some of the behaviours that affected his work as a consequence of having Parkinson's.

Bill: *"If people know then they want to help. If they don't know then they can't be expected to help or understand."*

This introduces the concept of level of disclosure. Bill did more than just tell others that he had Parkinson's, he explained to them what this meant. This could be contrasted with Ed's experience of taking leaflets containing information about Parkinson's to work but being fairly certain that nobody had read them. Ed was therefore in a situation that people knew of his diagnosis but were probably in the dark as to how it was affecting him on a day to day basis and perhaps at a loss as to how they could best support him. Initially Neil did not disclose his diagnosis and his tremor was interpreted as being the result of having drunk too much the previous night. Anna held a dinner party to tell her colleagues and felt that by doing this she was taking control of the disclosure part of dealing with her condition. Interestingly, taking this action was one of the strategies she adopted as a result of working with a counsellor following her diagnosis. She was the only participant that revealed having sought counselling specifically to cope with her initial diagnosis and its impact on her employment. Clearly there is a strong link between level of disclosure and all other themes hitherto discussed.

5.4.7 *Self-efficacy*

All participants talked of taking action to make the most of their situation post-diagnosis and also reported previous events in their lives and activities outside work that demonstrated a high level of self-efficacy. For instance, several participants talked of how they had changed jobs in the past because their work no longer gave them any satisfaction. There were several instances of taking on challenges in their private lives or ably coping with difficult situations. Despite moments of denial and despair, participants appeared pro-active in dealing with their Parkinson's.

Nell: *"I think I was starting to think "I've got to demystify this medical condition" and the only way you handle stuff is to face it head on and do it."*

Rob: *"Parkinson's just seems to be one of the things that's happened in my life and I'm interested, in a perverse sort of way, to see what's going to unravel. I mean, I wish I didn't have it but having got it, I'm not looking forward to the challenge but I'm not deterred by the challenge. I mean I could just stay home, lie down,*

watch telly and just become a moron and I think Parkinson's would consume me pretty quickly. Or I could try and do all the things I can, just being as normal as possible."

In another demonstration of self-efficacy, Neil talked of making changes to his bathroom to accommodate the disability that he presumed would be brought about by his Parkinson's in the future.

Neil: *"It was just planning, just having some control, management over something that I really have no control over. It just means that I've done something that will help down the track."*

The problem solving component of self-efficacy is demonstrated in the manner participants tried to resolve problems relating to their work situation by trying to take control of the situation, enlisting support from others through disclosure and altering the demands of the job in order for them to cope. As mentioned earlier, one participant was confident enough in her medical knowledge to alter her regime of medication to suit her work demands. Self-efficacy is therefore an essential part of dealing with work related issues following diagnosis with Parkinson's. Anna reflects on her level of confidence shortly after diagnosis as she was trying to re-negotiate her new role at work.

Anna: *"I look back and I think that I was probably feeling more vulnerable than I realised. I thought I was being quite cheeky."*

5.4.8 Depression

Although no clinical assessment was taken of depression as part of the interview, three participants reported taking medication for depression in relation to their Parkinson's. One participant suggested that the emotional difficulties that they experienced were the first symptom they noticed and were relieved when they received

a diagnosis of Parkinson's as it reassured them that they was not going mad. This participant clearly viewed depression as one of the symptoms of Parkinson's.

In contrast, another participant who was taking medication for depression spoke about mood fluctuations as an adjustment to accepting the diagnosis and dealing with fear of what the future might hold. As such, this respondent viewed depression as a temporary state. The third participant taking medication for depression spoke of a previous history of alcohol misuse. This is indication that there may have been pre-existing psychological difficulties for which alcohol represented self-medication. For this respondent, work was described as counteracting negative thoughts and perhaps making life worth living.

The remaining three interviewees did not mention depression at all. In contrast, they spoke of their general positive attitude towards life and how they believed that this helped them deal with Parkinson's.

5.5 Discussion

The aim of Stage One of this project, the qualitative study, was to explore the employment of PWP in order to understand more about the experience and to ascertain the factors that are perceived to have the greatest influence on QoL. This discussion reviews findings in accordance with the data emerging from the interviews.

5.5.1 *Time in employment and duration of diagnosis*

Since five out of the six participants in the interviews were still in employment, this research does not further our knowledge about time between diagnosis and loss of employment. The range of time since diagnosis varies and, based on previous research indicating a range from immediate withdrawal from work to remaining in work for up to 17 years (Schrage & Banks, 2006; Zesiewicz et al., 2007, Martikainen et al., 2006), this was to be expected. Of interest is that the one participant who had already left employment had been diagnosed for a shorter length of time than any of the other participants. This is in accordance with Schrag and Banks' (2006) finding that the duration of diagnosis does not relate to the time that PWP remain working. However, it is worth noting that this individual reported having symptoms for the second longest time of all participants. Also noteworthy is that in all cases symptoms had been present

for at least a year prior to diagnosis. In the case of the individual who left work after only a year and a half, symptoms were reported to have been present over ten years prior to diagnosis.

5.5.2 *Benefits of employment*

It was evident that all participants derived satisfaction from their work and were cognisant of the benefits of employment terms of QoL. One participant experiencing depression described work as the thing that kept him alive. This confirmed previous research that had shown the association between employment and QoL for people living with chronic illness (Aberg et al., 2009; Blalock et al., 2002; Dodel et al., 2007; Fleer et al., 2006; Heider et al., 2007; Koch et al., 2001) and specifically for people living with Parkinson's (Calne et al., 2008; Klepac et al., 2008).

Employment was described by participants in this study as beneficial in terms of providing social contact, and cognitive stimulation. Employment was also viewed as helping to maintain positive affect and provide a sense of purpose. This insight into PWP's assessment of the benefits of employment indicates that the psychosocial impact of work for people with chronic illness is no different from that of people in good health (Graetz, 1993; Liem & Liem, 1988; Murphy & Athanasou, 1999; Schwingel et al., 2009). Nevertheless, half of the participants reported taking medication for depression.

Of interest was that financial considerations were not presented as reasons for maintaining employment. This may have been because the children of all participants were adult or approaching adulthood or perhaps because the financial impact was assumed and therefore not worthy of mention. However, it appeared that QoL was more associated with work content rather than financial remuneration, as evidenced by the desire to work in a voluntary capacity following withdrawal from paid employment.

5.5.3 *Salient factors*

The themes that emerged as the most salient factors affecting PWP's work life were the demands of a job, fatigue, the control that a person has over their work, their access to and quality of social support and their level of self-efficacy. These factors appeared to be interdependent but will firstly be discussed separately.

5.5.3.1. *Job demands*

Consistent with previous research into the adverse effects of the physical and cognitive demands of work on people with chronic conditions, including Parkinson's (Baanders et al., 2002; Lillefjel et al., 2006; McCabe et al., 2008; Roessler et al., 2001; Rumrill & Fitzgerald, 2004), it seems clear from the current study that PWP leave employment partly due to job demands becoming overwhelming. This study therefore supports the proposal that the JSM has relevance to chronically ill populations in employment (Karasek, 1979).

Demands in the current study are recognized as both physical and cognitive. Physical demands are most notably related to problems with balance and fine and gross motor control, and cognitive demands relate to difficulties with attention, memory and organizational abilities. The participants in this preliminary study reported a wide variety of both physical and mental demands in relation to their jobs, thus highlighting the difficulty in measuring job demands in chronically ill populations where individuals are employed in extremely diverse jobs. This division of job demands corresponds to Munir et al.'s (2005) three types of work adjustments (physical, cognitive and social) although social aspects of employment were not discussed in the context of being demanding. However, significant time was given to talking about work-related social interactions, an indication that these social interactions are in fact demanding, even if viewed primarily as one of the most beneficial parts of work. This will be discussed in a later section.

5.5.3.2. *Fatigue*

Fatigue emerged as one of the most salient factors affecting work for PWP, confirming previous research that fatigue is more significant in influencing work participation rates of people with chronic illness (including Parkinson's) than illness specific symptoms (Dodel et al., 2007; Lee et al., 2008; McCabe et al., 2008; Munir et al., 2005; Zesiewicz et al., 2007). Since fatigue in Parkinson's is often cited as one of the most debilitating effects of the disease in terms of its effect on QoL, irrespective of employment status (Herlofson & Larsen, 2003), it is not possible to draw any conclusions as to the degree to which employment contributes to fatigue.

5.5.3.3. *Control*

The concept of control manifested in several ways in the current study. Participants talked about the initial loss of control at the time of diagnosis and the continuing sense of being controlled by the unpredictability of symptoms, uncertainty about what the future holds and an imposing regime of medical appointments and medication. This expression of loss of control due to the unpredictable nature of Parkinson's is consistent with previous research findings that people with illnesses with uncertain progression experience particular barriers to employment (Robinson, 2000) and are related to job stress (Merz et al., 2001).

The importance of having control over a work schedule was highlighted by participants' mention of an appreciation of an ability to make work related decisions either because of an authoritative position within an organization or due to self-employment. The demands of a job, fatigue, medical appointments and unpredictable symptoms appeared to be alleviated by an ability to have control over how to tackle these difficulties. Control therefore appeared to be described as moderating the effects of job demands. The positive manner in which such control was framed seems to indicate that the current study supports the application of the buffering hypothesis of the JSM to PWP, whereby job control moderates the effects of job demand (Van der Doef & Maes, 1999). It would also suggest that control at work may be associated with an elevated QoL, as evidenced by previous research (Behari et al., 2005; Koplak et al., 1999).

In contrast, those with less control over their work environment (those that were employed in positions of less responsibility) talked of the stress involved in having to negotiate time off for medical appointments and trying to gain some control over the demands of their work through manipulating their medication. This also supported the potential relevance of the JSM (Karasek, 1982) to a population of chronically ill workers.

This study also suggested, in accordance with previous research, that control would only be effective in reducing work-related stress if it was appropriate to alleviating specific job demands (Sparks & Cooper, 1999; Van der Doef & Maes, 1999; Wallace, 2005). For instance, an employer reducing an employee with Parkinson's hours would not necessarily assist since the unpredictability of the symptoms may mean that they are at their worst exactly when job demands are at their highest. Alternatively, flexibility allowing an individual to work when they feel at their best and not work

when at their worst, could appropriately accommodate the fluctuating symptoms of PWP. Results also highlight the negative effect ensuing from others taking control away from PWP by making work related decisions on their behalf.

5.5.3.4. *Social Support*

As previous research has found, support from other people appears to be crucial to PWP in helping them deal with problems faced at work (Gignac, 2005; Koch et al., 2005; Lidal et al., 2007; Patel et al., 2007; Pryce et al., 2007; Roessler et al., 2005; Rumrill et al., 1999). Employers were acknowledged for their role in assisting to make changes to accommodate employees with Parkinson's and permit time off to attend to medical appointments. Social support was also forthcoming from colleagues willing to take on tasks that the PWP were finding difficult due to their condition. It seems that social support may assist in buffering the effects of overwhelming demands on a PWP at work, consistent with previous assessments of its role in the JSM (Vanreolen et al., 2009), although it is not clear who provides the most effective work related social support in terms of its influence on PWP well-being.

Of paramount importance to receiving appropriate social support appears to be disclosure, without which none of the support described by PWP would have been forthcoming. Prior to disclosure, other assumptions about the physical manifestations of Parkinson's are often made (Abudi et al., 1997; Lyons & Tickle-Degnen, 2003; Nijhof, 1995), whether this is out in public or in the workplace. An employee that is thought to be regularly recovering from an alcohol-fuelled night out is unlikely to be viewed favorably by an employer. In line with previous research, employers appear generally open to accommodating PWP if they are fully informed of the impact of the illness, as has been found in relation to accommodating other chronic conditions (Gignac, 2005; Jackson et al., 2000; Rumrill & Hennessey, 2001). All participants in this current study had disclosed to their employer and colleagues that they had Parkinson's. It is not known how much information they had provided in terms of how others might be able to assist them.

Despite the numerous incidences of supportive social interaction, PWP are also subject to less helpful responses from others. Withdrawal has previously been found to be a common response from friends and family (Dakof & Mendelsohn, 1986; Ellgring et al., 1993; Hodgson et al., 2004) and this appears to be mirrored in the workplace. PWP find they are overlooked, perhaps through ignorance on the part of others as to the

real implications of the condition. Leaving PWP out of particular work decisions may be designed with the intention of alleviating stress but instead leaves the individual concerned feeling isolated and ignored. Full disclosure in terms of the effect that Parkinson's has on a person's work life would seem to be one way that this type of negative reaction could be prevented.

In summary, although the positive effects of social support appear to help counteract the problems faced at work by PWP, there also appears to be a negative impact from the responses of others. It is likely that this type of response would exacerbate difficulties already resulting from working whilst managing Parkinson's and may contribute to workplace stress. It may be more meaningful to divide social support into two constructs when considering Parkinson's in the workplace; firstly, positive social support (normally termed social support), and secondly, negative social support.

5.5.3.5. *Self-efficacy*

Self-efficacy seemed to be evidenced in PWP by repeated reference to meeting the challenges that the condition presents. Facing adversity with a positive frame of mind and dealing with problems and setbacks appeared to be a recurring theme, whether it was in relation to work or home and family life, or prior to or since diagnosis with Parkinson's. Since self-efficacy has previously been established as playing a major role in maintaining employment for people with chronic conditions (Roessler & Rumrill, 1994) it is not surprising that those interviewed (predominantly working whilst managing their Parkinson's), displayed a high levels of self-efficacy. The interviewee who had made the most changes to their work life in order to accommodate Parkinson's was the one self-employed participant who was likely to enjoy a high level of self-efficacy since self employment has previously been found to be associated with self-efficacy (Bradley & Roberts, 2004). Designing a work schedule so as to be able to sleep when Parkinson's required was no mean feat and an achievement that would have been impossible with out a high level of self-efficacy.

The participants in this current study were recruited through Parkinson's Victoria and their participation in this study was voluntary. Their association with a Parkinson's related association and willingness to participate in this study are an indication that this group of people as a whole possess a higher level of self-efficacy than might be found in a random sample of PWP. Their apparent high level of self-efficacy cannot be assumed to be that of PWP in general.

5.6 Conclusion to Stage One

The qualitative study that formed Stage One of the current research provided an insight into the reality of working whilst managing Parkinson's. PWP gain great benefit from employment in terms of social interaction and maintaining a sense of purpose. Nevertheless, this study clearly presents the challenges faced by PWP wishing to remain in employment. The factors that appeared to be of greatest concern to PWP in the workplace were job demands, fatigue, control, social support and self-efficacy. It seemed apparent that these factors were paramount in influencing the level of stress experienced at work and were therefore likely to have a corresponding effect on PWP's QoL. The qualitative nature of this study means that these associations are inferred and would need to be tested in a quantitative manner in order to gain statistical evidence.

The grounded theory approach meant that there were several factors that have previously been found to be associated with maintaining work that were not mentioned. For instance, depression has been found to be one of the dominant predictors of QoL in PWP (Behari et al., 2005; Carod-Artal et al., 2008; Cubo et al., 2002; Kuopio et al., 2000; McCabe et al., 2009; Reuther et al., 2007; Schrag, 2006; Slawek et al., 2005) and has been found to be more influential than the physical limitations resulting from chronic illness in determining a person's ability to remain in employment (Munir et al., 2005). A direct question regarding depression may have elicited more content in this regard. It is possible that the stigma associated with depression had prevented interviewees from raising the matter unsolicited, or perhaps a group of people with high levels of self-efficacy chose to focus on positives rather than negative attributes of self. Furthermore, depression amongst participants may have been controlled through medication so not currently influencing their work experience.

Level of education was also not mentioned by interviewees although the predominance of professionals or semi-professionals indicated that the majority of interviewees were highly educated. Their employment status is validation for Rumriill et al.'s (2004) model that states that people with chronic illness with better education are more likely to be employed than those with less education or skills.

The qualitative evidence provided by this study is also limited by its focus on PWP who had all disclosed their condition to their employer. A very different picture may have resulted from interviews with PWP who were hiding their condition at work. Similarly, the people interviewed were predominantly proactive professionals with a

high level of self-efficacy, therefore placing them in a position to be pro-active in dealing with their condition and how it affected their employment.

Despite the importance previously attributed to health providers in supporting a person with a chronic illness in obtaining or maintaining employment (Detaille, Haafkens, & Van Dijk, 2003; Johnson et al., 2004; Koch et al., 2005; Pryce et al., 2007; Varekamp & van Dijk, 2006), results from these interviews indicate that PWP do not rate their health providers as important in relation to workplace issues. Health providers were mentioned in these interviews in relation to an ability to attend appointments rather than as supportive in terms of employment concerns. Perhaps a question relating directly to the role of health providers might have elicited a different response but this was not appropriate to the grounded theory approach adopted during the interviews.

Previous studies that have examined employment for PWP have concentrated on symptomatic and demographic factors that are immutable rather than psychosocial factors that may be subject to improvement with intervention (Schrag & Banks, 2006; Zesiewicz et al. 2007). Martikainen et al. (2006) examined adjustments at work for PWP but did not investigate the factors that dictated whether or not these adjustments took place. The themes that have emerged from this current study place the management of employment concerns for PWP in the realm of a model of job stress based on psychosocial factors rather than demographic variables associated with coping with chronic illness that is worthy of further exploration.

CHAPTER SIX

STAGE TWO: QUANTITATIVE STUDY

6.1 Introduction

The aim of this study was to identify the factors that most influence the work related QoL of PWP, using an adapted version of the JSM for the first time with this population. Factors that have already been established as either significant predictors or possible predictors of QoL, depression or employment status in PWP, but not components of the JSM, need necessarily to be taken into account (e.g. illness severity and duration, gender, age and education). In the absence of sufficient Parkinson's related research addressing workplace concerns, the preliminary qualitative interviews were designed to identify factors reported to be most influential in the day-to-day work life of PWP. The second stage of this project is quantitative in nature and based on results from the initial qualitative study, together with information gleaned from the preliminary literature review as presented in the introduction. This study is cross-sectional in design as longitudinal research is beyond the scope of the current project.

The themes that emerged from the preliminary study were fatigue, job demands, control, positive and negative social support and self-efficacy. Three of these themes (job demands, job control and positive social support) constitute the key elements of the JSM of work associated mental health (De Lange et al., 2004). However, in order to use this approach, it was necessary to identify the role played by the remaining factors, fatigue, negative social support and self-efficacy.

When testing the JSM, Noblet (2003) advocated taking into consideration environment specific factors in order to give a clearer picture of employment related well-being. It is possible that the constructs of fatigue, negative social support and self-efficacy that emerged from Stage One of this project constitute these environment specific factors for PWP. It may be that the addition of fatigue and self-efficacy to the JSM will make it more relevant to PWP. This second stage therefore proposes to use the JSM as a framework for confirming the significance of the workplace factors identified in the qualitative study for PWP. In conceptualising the second stage of this project, further consideration of the constructs involved was necessary in order ensure appropriate measurement.

6.1.1. *Job Demands*

In the original conception of the JSM (Karasek, 1979) job demands were restricted to the psychological demands of the job. Given that the limitations imposed by the symptoms of Parkinson's and other chronic conditions are both physical and psychosocial in nature (Baanders et al., 2002; Munir et al., 2005), it seems appropriate that the scope of Karasek's definition of job demands is broadened for this population to encompass physical and social demands as well as psychological demands. This approach is in keeping with findings of the first stage of this project, whereby demands were identified as being both cognitive and physical. Social interactions at work were not overtly identified as being demanding, but the preponderance of their mention was interpreted as their constituting part of job demands.

The current study is likely to be affected by the difficulties presented when measuring job demands amongst a population employed in diverse occupations. It would be impossible to restrict the sample to PWP of one profession only as this would limit the number of people eligible to participate and produce a sample too small to analyse. Questions used to measure job demands therefore need to be generic in nature so as to encompass demands of all types of jobs.

6.1.2. *Job control*

Control has previously been identified as influencing PWP's QoL (Koplas et al., 1999) and lack of control has been linked to causing stress at work and creating difficulties in maintaining employment for people with progressive illnesses such as Parkinson's (Merz et al., 2001; Robinson, 2000). Issues of control emerged from Stage One of this project in relation to medication, the unpredictability of Parkinson's symptoms and time off for medical appointments. It is difficult to distinguish between control and lack of control as generic constructs, and the concept of job control that has specific relevance to work. Medication and unpredictability of symptoms are issues that pose difficulties in all areas of an individual's life whereas time off for medical appointments is specific to work. As the current study aims to identify areas suitable for intervention in the workplace in order to improve work life for PWP, the concept of control needs necessarily to be restricted to job control and measured accordingly. Karasek's (1979) definition of job control is the degree to which an individual has the

authority to make decisions about how and when the various components of a job are accomplished. This definition therefore forms the basis for measurement of job control in the current study.

6.1.3. *Positive Social Support*

Positive social support is beneficial to an individual when it is appropriate to a particular situation (Noblet & Rodwell, 2009; Vanroelen et al., 2009). Positive social support in relation to work may emanate from employers/supervisors, colleagues or friends and family and may be in the form of instrumental or emotional support. It is imperative that positive social support in the current study is measured to encompass all its diverse forms since participants will necessarily be working under varying conditions with different challenges that demand appropriate types of positive social support. It is also necessary to distinguish between different sources of positive social support rather than view it as a global construct in terms of who is providing that support.

Results from Stage One of the current study support the buffering hypothesis of the JSM (Van der Doef & Maes, 1999), indicating that positive social support may protect PWP against the effect of job demands on job strain (e.g. assistance from colleagues in undertaking tasks made difficult by Parkinson's). The concept of negative social support was not included in the original JSM, nor has it been considered in subsequent research investigating the validity of the JSM to various populations. Indeed, negative social support has not been widely investigated in other contexts but its inclusion appears crucial if the current study is to reflect results from Stage One and fully incorporate the effects of social interactions in the workplace on job strain.

6.1.4. *Negative social support*

Negative social support is characterised by unsupportive behaviours towards others, distinguishing it clearly from a lack of positive social support (Norton et al., 2005). Such behaviours may include withdrawal, criticism or any actions that might be perceived by the person living with the chronic condition as unhelpful or causing distress. Negative social support is related to depression in people living with chronic illness (Ray, 1992; Revenson, 1991;). This effect is independent of the relationship

between positive social support and psychological well-being and has received far less attention in research.

In a review of literature pertaining to negative social interactions, Lincoln (2000) found that, when no particular source of support is specified, the constructs of positive and negative social support are unrelated to each other. However, investigations into negative social support where the source of support is identified (e.g., support from a spouse) have shown positive and negative social support to be related. Lincoln further concluded that the adverse effect of negative social support on psychological well-being may be greater than the beneficial effect of positive social support, suggesting that in studies such as this current research, it is more important to investigate the effect of negative social support than positive social support. The distinction between positive and negative social support and the source from which the support emanates is therefore crucial to the current study and needs to be considered in the interpretation of results.

Manne and Schnoll (2001) established that negative support is characterised by the actions of criticism and withdrawal. Norton et al. (2005) confirmed this finding in an assessment of negative support received by people with ovarian cancer from family and friends. The results of Stage One of this project provide examples of withdrawal but not of overt criticism. Overt criticism may be less likely to emanate from people at work whose relationships with PWP are less permanent than those with family, and perhaps therefore more likely to be damaged by critical interactions. However, some interactions reported in Stage One could be perceived as demonstrating lack of confidence in work ability and therefore as constituting covert criticism (e.g. relieving PWP of tasks without consultation and thereby making the job less interesting and the PWP feel invisible). Stage One results highlight the role of negative types of social support in influencing the workplace experience of PWP and suggests that negative social support may interact with job demands to worsen the work experience.

6.1.5. *Self-Efficacy*

In relation to chronic illness and employment, self-efficacy in people with MS has been established as playing an important role in determining employment status (Roessler & Rumrill, 1994). Individuals with a high level of self-efficacy in this study were more likely to be in employment than those with low self-efficacy. Neither self-

efficacy in relation to the employment of PWP, nor self-efficacy in relation to the QoL in PWP has been investigated. However, individuals with high self-efficacy have been found to cope better with the demands of day-to-day living than those with low levels of self-efficacy (Fujii et al., 1997). As a dominant theme emerging from Stage One of this research, self-efficacy presents as a potential environmental factor that may need to be added to the JSM in order to make it appropriate for PWP and other chronic conditions. As referred to earlier in Chapter Four, self-efficacy has been found to moderate the effects of job demands and job control on job strain and is likely to have to play a similar role with PWP in the workplace.

6.1.6. *Fatigue*

Fatigue is a dominant theme of PWP and, indeed, people living with chronic illnesses, and it would therefore seem necessary to include fatigue within a JSM adapted to people with chronic illness. Although fatigue could be considered as being exacerbated by the demands of employment and therefore constitute an outcome measure, evidence suggests that fatigue exists with or without employment and may even be worse for those not working (Baanders et al., 2002). In the current study therefore, fatigue is a potential confounding variable influencing an individual's QoL and needs to be taking into account when testing the JSM. Fatigue was therefore treated as a generic symptom of Parkinson's for the purposes of this study.

6.1.7. *Job Strain*

There has been no uniformity in the measurement of job strain in research validating the JSM. Job strain was originally conceived as being the combined effect of diminished health, exhaustion, depression and low job satisfaction (Karasek, 1979). This presents a problem when measuring job strain amongst a chronically ill population as the level of general health and fatigue exists independent of employment. It is also not possible to measure any improvement or deterioration in health caused by working as employment generally exists prior to the chronic condition. This study has elected to focus outcome measures on QoL and depression, taking into account the physical symptoms of PWP.

As discussed earlier, using a measure of QoL permits assessment of how much certain factors (e.g. Parkinson's symptoms, job demands) affect normal daily function. A measure of QoL can be chosen to represent the particular areas of life that are important to a particular population, in this instance, people of working age. A measure that is not specific to Parkinson's allows transference to and comparisons with other chronically ill populations and would give the current research future application.

Depression in Parkinson's has been found to be closely associated with QoL, particularly for younger PWP (Behari et al., 2005; Carod-Artal et al., 2008; Cubo et al., 2002; Kuopio et al., 2000; Reuther et al., 2007; Schrag, 2006; Slawek et al., 2005). Depression has also been found to be more influential than physical limitations in determining whether a person is able to cope with the demands of a job (Munir et al., 2005). Even though depression did not feature prominently in this study's qualitative data, its prominence in Parkinson's QoL literature cannot be ignored. As discussed earlier, its minimal presence in Stage One data may have been due to perceived stigma associated with depression, absence of current symptoms of depression due to pharmaceutical interventions or reluctance of PWP with depression to volunteer for this a project. It seemed appropriate that depression should be used as a second measure to assess job strain, as it was with the original JSM (Karasek, 1979).

6.1.8. *Aims and Hypotheses*

Based on previous research and the preliminary qualitative study of this current research, the aim of Stage Two was to use the JSM as a framework to establish quantitatively the work-related factors that influence the psychological well-being and QoL of PWP in employment. According to the JSM, job strain results from the additive effects of job demand, job control and social support (see Section 4.1). Furthermore, the JSM proposes that job control and social support buffer the effect of job demands and job control on job strain (see Section 4.3 and 4.4). Self-efficacy has also been demonstrated to buffer the effects of job demands and job control on job strain (see Section 4.5). In the context of Parkinson's, the JSM needs to be tested whilst accounting for demographic and illness related factors that are known to contribute to QoL and psychological well-being (e.g., Parkinson's severity and duration). To enhance the model according to previous adaptations of the JSM (Noblet, 2003; Noblet

et al., 2008), factors emerging from the qualitative study of this current research were added. Fatigue was viewed as a symptom of Parkinson's and taken into account in analysis and social support was divided into positive and negative social support. The distinction was made between different sources of positive social support, (from employers, from colleagues and from friends and family). The following hypotheses were established:

Hypothesis 1: In order to establish the existence of relationships between the constructs under consideration and outcome measures of QoL and depression in PWP in employment, correlational analysis was conducted. It was hypothesised that job control, positive social support and self-efficacy in PWP in employment would be positively related to QoL, that Parkinson's severity, fatigue, job demands and negative social support would be negatively related to QoL. It was also hypothesised that Parkinson's severity, fatigue, job demands and negative social support would be positively related to depression, job control, positive social support and self-efficacy would be negatively related to depression. It was predicted that Parkinson's duration would not be related to either QoL or depression.

Hypotheses 2: It was hypothesised that (after controlling for Parkinson's severity, Parkinson's duration, fatigue, age, gender and education) the constructs of job demands, job control, positive social support, negative social support and self-efficacy would predict QoL and depression in PWP in employment. This was tested using hierarchical regression analysis.

Hypothesis 3: It was hypothesised that (after controlling for Parkinson's severity, Parkinson's duration, fatigue, age, gender and education) job control, positive social support and negative social support would moderate the effect of job demands on QoL and depression in PWP in employment. This was tested using hierarchical regression analysis.

Hypothesis 4: It was hypothesised that (after controlling for Parkinson's severity, Parkinson's duration, fatigue, age, gender and education), self-efficacy would

moderate the effect of job control and job demands on QoL and depression in PWP in employment.

6.2. Method

6.2.1. *Participants*

Subsequent to initial screening the sample size was 116 of which 54% were male and 46% female. The age of respondents ranged from 36 to 68 years ($M = 53.61$, $SD = 7.07$). The majority of the participants were married or in *de facto* relationships (75%), 16% were divorced, 8% were single and one participant was widowed. A total of 76% of the sample were born in Australia, 14% in the UK and 97% nominated English as their first language. Over half of the sample had university qualifications (66%), with 40% of respondents citing a tertiary qualification as their highest level of education attained and 26% having postgraduate qualifications. Trade qualifications were held by 16% of the sample, and 5% had not completed secondary school. In response to the question relating to their place of residence, 59% of participants were urban dwellers, 24% described their place of residence as 'regional' and 17% of respondents said they lived in rural or remote areas.

6.2.2. *Materials*

The online questionnaire consisted of demographic and diagnosis related questions, questions relating to the nature of work and work status and established psychometrically validated psychosocial scales. These questions were preceded by an explanation of the purpose of the study and contact details were provided for participants who might wish to access counselling or make a complaint subsequent to filling out the questionnaire. Participants were also informed of the confidential nature of the study and that completion of the questionnaire would be regarded as constituting informed consent (see Appendix E). A paper copy of the questionnaire was also prepared for those that requested to fill in the survey this way.

6.2.2.1 *Demographic questions*

Demographic questions related to gender, age, marital status, place of birth, first language, highest level of education and place of residence.

6.2.2.2 *Employment related questions*

Participants were asked if they were in full- or part-time employment, the nature of their employment and the size of the organisation for which they worked. Participants were also asked about disclosure, whether they had told their employer and colleagues that they had Parkinson's and whether they had changed job, or adapted their job, as a consequence of having Parkinson's.

6.2.2.3 *Medical questions*

Questions relating to participants' medical condition covered the length of diagnosis, length of symptoms and the presence of other medical conditions. In accordance with Schreurs et al. (2000), severity of Parkinson's was measured by asking participants to indicate whether they experienced each of the eight predominant motor symptoms. These symptoms were slowness of movement, stiffness, posture problems, trembling, problems initiating movement, muscle weakness, speech problems and problems with facial expression. The number of symptoms was totalled to give a Parkinson's severity score ranging from 0-8. The mean severity score using this form of measurement is 4.14 ($SD = 1.86$) and higher scores indicate more severity (Schreurs et al.). The validity of using symptoms to assess severity is evidenced by their relationship to all domains of functioning (mobility control, psychological autonomy, communication and social behaviour) (Schreurs et al.) and constitutes an alternative self-report method of assessing severity in the absence of medical clinicians involved in a study.

6.2.2.4 *Fatigue Severity Scale (FSS; Krupp et al., 1989)*

The FSS is a nine-item questionnaire designed to assess the impact of fatigue on daily activities with particular relevance to medically ill populations. Respondents are required to rate nine statements relating to the effect of fatigue on their lives. Examples of statements were 'My motivation is lower when I am fatigued', 'I am easily fatigued' and 'Fatigue interferes with my physical functioning'. Ratings were made using a seven-point Likert scale where 1 = strong disagreement with the statement and 7 = strong agreement with the statement. A total FSS score was obtained by summing the scores for the nine items. The possible range of total FSS scores was 7-63, with people with Parkinson's classified as suffering from significant fatigue when they score 41 or more (Herlofson & Larsen, 2002). The FSS has demonstrated excellent reliability

(Cronbach's alpha > .90) (Green et al., 2000). Comparable reliability was demonstrated in the current study (Cronbach's alpha = .93).

6.2.2.5 *Job Demands*

In accordance with Karasek et al. (1979) job demands were measured by responses to a single question, "How would you best describe the work you do?" Three responses were proposed in answer to this question, 'physically demanding', mentally demanding' and 'socially demanding'. Respondents rated each of these three responses using a 5-point Likert scale where 1 = 'not at all', 2 = 'a little', 3 = 'moderately', 4 = 'quite' and 5 = 'extremely'. The three scores were summed to produce a job demands total score ranging from 2-15 where 2 = very low job demands and 15=extremely high job demands. There are no pre-existing measures of reliability for this scale as it was constructed specifically for this research. This measure of job demands only exhibited moderate reliability (Cronbach's alpha = .56). When physical job demands were excluded, a combination of mental and social demands produced a measure with higher reliability (Cronbach's alpha = .65) and total scores ranging from 2-10. This two dimensional scale was therefore used for the current study. Using only the psychosocial measure of job demands was more in keeping with the theoretical basis of the JSM (Karasek, 1979).

6.2.2.6 *Job Control, Cognitive Demand and Production Responsibility Scale (JCCDPS; Jackson et al., 1993)*

Job control was measured using the ten job control items of the JCCDPS. Job control consisted of two constructs, timing control and method control. Timing control, the amount of freedom an employee has to choose how work is scheduled, comprised four questions. Two questions related to when work is done (e.g., do you decide when to start a piece of work?), one question related to the pace of work (e.g., do you set your own pace of work?) and one question related to the order of the work (e.g., do you decide on the order in which you do things?). Method control, the amount of freedom an employee has to choose how work is carried out, comprised six questions. Four questions related to an individual's latitude to determine methods used at work (e.g., do you plan your own work?), one question related to the quality of work produced (e.g., can you control the quality of what you produce?) and one question related to the quantity of work produce (e.g., can you control how much you produce?).

Responses to these questions were rated on a 5-point Likert scale where 1 = 'not at all', 2 = 'just a little', 3 = a moderate amount', 4 = 'quite a lot' and 5 = 'a great deal'. A total score for job control was obtained by summing the scores from each of the 10 items (range 10-50). A total job control of 10 would indicate that an individual had no control at all over how they did their work and a total job control score of 50 would indicate that an individual was able to exert a very high level of decision latitude over to how work was done. Amongst a sample of workers with a mean age of 33.00 ($SD = 11.66$), the mean scores for job control were 31.30 ($SD = 9.40$) (Wall et al., 1996).

Both sub-scales have demonstrated good reliability (timing control Cronbach's alpha = .79-.85 and method control Cronbach's alpha = .77-.80) (Jackson et al., 1993). The two sub-scales combined as they have been in the current study have also demonstrated good reliability (Cronbach's alpha = .86) (Wall et al., 1996). In the current study, the combination of these two subscales to form a measure for job control demonstrated excellent reliability (Cronbach's alpha = .92).

6.2.2.7 *Social Support Scale (SSS; Caplan et al., 1980)*

Positive social support was measured using the SSS, designed to assess levels of job related support available to an employee from both people at work and friends and family outside work. The scale consists of four questions, two relating to available instrumental support and two questions relating to emotional support. The instrumental support questions were 'How much does each of these people go out of their way to do things to make your work life easier for you?' and 'How much can each of these people be relied on when things get tough at work?' The emotional support questions were 'How easy is it to talk with each of the following people?' and 'How much is each of the following people willing to listen to your personal problems?' Participants respond to each of these four questions three times, firstly, in relation to a worker's employer/immediate supervisor, secondly, in relation to colleagues at work, and, thirdly, in relation to the respondent's family and friends. There are 12 responses in total.

Responses are rated on a 5-point Likert scale where 0 = 'don't have any such person', 1 = 'not at all', 2 = 'a little', 3 = 'somewhat' and 4 = 'very much'. Scores from the four items relating to each source of positive social support are summed to produce a positive social support total score for each of the different sources of support (e.g., employer, colleagues, family and friends). The range of this score is 0-16. A score of 0

would indicate that an individual has no positive social support at all from this source and a score of 16 would indicate that they enjoy a high level of social support. The four items relating to positive social support from an employer/supervisor have shown excellent reliability (Cronbach's alpha = .91) (Lee & Ashforth, 1993). The combined scores for support received from supervisors and work colleagues have demonstrated good reliability and validity as a single measure (Cronbach's alpha = .80) (Lim, 1980 cited in Fields, 2002). Scores for support received all sources of positive social support demonstrated excellent reliability for the current study (employers Cronbach's alpha = .96, colleagues Cronbach's alpha = .92, family and friends Cronbach's alpha = .83).

6.2.2.8 *Partner Responses to Cancer Inventory (adapted version) (PRCI; Manne & Schnoll, 2001)*

Negative social support was measured using an adapted version of the PRCI. The original version of this inventory included both beneficial and unhelpful types of responses to a partner with cancer. The current study only used items relating to unhelpful types of responses (negative social support), made up of items based on the constructs of criticism and withdrawal. The wording of items from the PRCI was adapted so that questions referred to responses from people in the workplace rather than from family members (e.g., 'How often has your partner responded in this way?' was changed to 'How often have people at work responded in this way?'). This adapted scale is referred to henceforth as the negative social support scale.

The negative social support scale consisted of thirteen items describing possible ways that people at work have responded to a PWP when help was required to deal with their illness and treatment during the past 6-18 months. Six items related to criticism (e.g., seemed angry or upset with you when doing things to help you). Seven responses related to withdrawal (e.g., avoided being around you when you were not feeling well). Responses were rated on a 4-point Likert scale were 1 = 'never responded this way', 2 = 'rarely responded this way', 3 = 'sometimes responded this way' and 4 = 'often responded this way'. Response scores were summed to produce a total negative social support score with a range of 13-52 where 13 indicated that an individual experienced very little negative social support in relation to work and a score of 52 indicated that an individual experienced a high level of negative social support in relation to work.

The dimensions of criticism and withdrawal that constitute part of the PRCI (Manne & Schnoll, 2001) have demonstrated good reliability (Cronbach's alpha=.88).

The negative social support scale derived from the aforesaid inventory demonstrated excellent reliability for the current study (Cronbach's alpha=.96).

6.2.2.9 *General Self-Efficacy Scale (GSE; Schwarzer & Jerusalem, 1995)*

Self-efficacy was measured using the GSE, a scale developed as a measure of perceived self-efficacy in order to predict an individual's ability to deal with daily hassles as well as adapt to cope with stressful life events. As such it was designed for use with people living with adverse medical conditions in order to assess the effect their condition may have on QoL.

The GSE is uni-dimensional and consists of ten statements reflecting the respondent's internal attribution of success in relation to problem solving (e.g., when I am confronted with a problem, I can usually find several solutions), persistence (e.g., it is easy for me to stick to my aims and accomplish my goals), and ability to cope with unforeseen difficulties (e.g., I am confident that I could deal efficiently with unexpected events). Respondents rated items using a 4-point Likert scale where 1 = 'not at all true', 2 = 'hardly true', 3 = 'moderately true' and 4 = 'exactly true'. Scores on items are summed to produce a total self-efficacy score with a range from 10-40 where a score of ten indicates that an individual perceives themselves to have a very low level of self-efficacy and a score of 40 indicates an individual perceives themselves to have a very high level of self-efficacy.

The GSE has demonstrated good reliability (Cronbach's alpha range = .75 - .91) (Schwarzer & Jerusalem, 1995). For the current study, the reliability was excellent (Cronbach's alpha = .93). The GSE has also been shown to be a valid measure of self-efficacy for use with populations living with neurological conditions (Zotti et al., 2007).

6.2.2.10 *Depression Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995)*

Depression was measured using the depression items of the short-form version of the DASS-21). The DASS-21 is a widely used instrument for measuring levels of distress using the three constructs of depression, anxiety and stress. The seven items relating to depression form the depression scale for the purposes of the current study. Each item is a statement to which participants are asked to respond by indicating how much that statement has applied to them over the past week (e.g., I couldn't seem to experience any positive feeling at all). Statements are responded to on a 4-point Likert

scale were 0 = 'did not apply to me at all', 1 = 'applied to me to some degree, or some of the time', 2 = 'applied to me to a considerable degree, or a good part of the time' and 3 = 'applied to me very much, or most of the time'. A total depression score is calculated by summing the scores from each of the seven items (total range = 0-21). A total score of 0-9 is deemed to be normal for someone not experiencing depression, 10-13 indicates the presence of mild depression, an individual with moderate depression is likely to score 14-20, a score of 21-27 is an indication of severe depression and scores over 27 are extremely severe.

The DASS-21 has exhibited high reliability (Cronbach's alpha = .82) amongst a non-clinical sample of over 1,500 (Henry & Crawford, 2005). The DASS-21 exhibited excellent reliability for the current study (Cronbach's alpha = .93).

6.2.2.11 *Quality of Life Scale (QoLS; Chibnall & Tait, 1990)*

QoL was measured using QoLS, a seven-item scale originally designed to assess QoL in people living with chronic pain. The seven items of the QoLS encompass seven areas of daily living relevant to people of working age: hobbies and recreation, family life, social life, daily living, sex life, educational and intellectual life and hopes and expectations for the future. Respondents are asked to rate these areas according to how satisfying that area of their life is. Ratings are made on a 7-point Likert scale where 1 = 'totally satisfying', 4 = 'moderately satisfying' and 7 = 'completely satisfying'. Total QoL scores are calculated by summing the scores from all seven items resulting in a range of 7-49 where a score of seven would indicate a very low QoL and 49 would indicate a very high QoL. The QoLS has demonstrated good reliability (Cronbach's alpha=.82 amongst a sample of people experiencing chronic pain). The QoLS exhibited very high reliability for the current study (Chronbach's alpha = .88).

6.2.3 *Procedure*

Once the questionnaire had been created, ethics approval was sought and given from the Swinburne University's Human Research Ethics Committee (Appendix F). A flyer was prepared asking for PWP who were in employment to voluntarily complete the survey (see Appendix G). The flyer provided details of the purpose of the study and the online location of the questionnaire. Contact details of the researchers were also provided for those that might wish to obtain a paper copy of the survey. The questionnaire was placed online using Opinio, a survey software application available

through Swinburne University of Technology. Paper copies were printed, and packaged with a stamped, self-addressed envelope for return. The questionnaire was available for a period of approximately 18 months. Participants were recruited in several ways.

The aim was to obtain a sample of PWP who were working either full- or part-time in Australia. It was also hoped that a proportion of the participants would not be associated with a Parkinson's support organisation. As has previously been noted, a sample obtained solely from Parkinson's organisations biases the sample towards those that are active in seeking support. Participants were therefore recruited in a number of ways: (1) notices were placed on the websites of various state Parkinson's organisations as well as in their newsletters; (2) contact was also made with organisers of various web-based chat rooms for people with Parkinson's, asking for volunteer participants; (3) contact was made with the organisers of support groups for younger people with Parkinson's requesting that they make their members aware of the study; (4) flyers detailing the study and requesting participation were made available at various Parkinson's focused events (national conference, seminar for newly diagnosed, sponsored walk); and, finally, (5) flyers were made available at movement disorder clinics in Victoria, and (6) an advertisement was placed on Facebook for a period of 3 months, targeting Australians of working age (see Appendix H). This last two strategies were used not only to attract more participants, but to also fulfil the aim of gaining data from people with Parkinson's who were not necessarily involved with and accessing support and information from a Parkinson's organisation. The Facebook advertisement was paid for by a combination of funds from Swinburne University and the researcher, a cost being incurred each time that the advertisement was clicked on. This advertisement appeared only on Australian Facebook pages.

Data was downloaded from Opinio and transferred to PASW Statistics application for analysis. Data obtained from paper and pencil questionnaires (3 completed surveys) was entered manually.

6.2.4 *Analysis*

Data was analysed using the PASW Statistics package, Version 18.0. Preliminary screening revealed two cases with more than 50% of the data missing and these were deleted. A third case was identified with a disclosed age of 16 years. As parental consent would be required to include data obtained from a minor and there was no provision for this in the online survey, this case was also deleted. In cases were less

than 30% of the data was missing for a particular scale, the missing value was replaced with the mean value (Tabachnick & Fidell, 1996). A total of 23 missing values were replaced with mean values.

Examination of the data for univariate outliers revealed one outlier for age and this case was removed for purposes of analysis (the age of this respondent was 19 years). A second outlier was detected for length of diagnosis, a participant who had been diagnosed for 17 years. This respondent's data was also deleted. The variables met the assumptions of homoscedasticity and linearity. Many of the variables were skewed but given the nature of the sample, transformations were not applied (Tabachnick & Fidell, 1996). All scales with the exception of job demands exhibited a very high level of reliability (a Cronbach's Alpha of greater than .9). The reliability of job demands was moderate. A power analyses using G*Power indicated that based on an effect size of .2, $\alpha = .02$ the total sample size required was 68 to conduct a series of regression analyses involving 10 predictors. The total sample in this study was 116 was therefore sufficient to undertake the regression analyses.

6.3

Results

6.3.1. *Employment status*

In relation to employment status, over half the respondents worked full-time ($n=76$) and the rest were working part-time ($n=40$). There was a wide variety of type of employment with the majority of occupations appearing to be professional or semi-professional. Almost half the respondents were working for large companies with over 200 employees (46%), 20% worked in small companies with less than 20 employees, 21% were self-employed and the remainder worked in medium sized companies. Just over half of respondents were employed in jobs that involved public speaking (51%). Only 5% of respondents described their jobs as highly physically demanding. The mean time that respondents had been in their current employment was about 13 years but there was a wide range from having just started to 45 years ($M=12.65$, $SD = 10.06$).

The majority of respondents were still in the same job as they were at the time of diagnosis (76%) with only 20% reporting having changed their job due to Parkinson's. Less than half the respondents reported having changed their jobs to accommodate the effects of Parkinson's (44%) and 42% said that they had reduced the number of hours they worked subsequent to diagnosis.

In relation to disclosure of their diagnosis at work respondents were more likely to disclose to their colleagues than to their employer. Although 75% of respondents had disclosed to their colleagues and 68% of respondent had told their employer of their diagnosis, only 59% and 53% respectively had explained how it affected them.

6.3.2 Health status

As can be seen from Table 3 below, the most common symptoms experienced by respondents were slowness of movement, stiffness and tremor. The number of symptoms experienced, indicating a level of Parkinson's severity, ranged from one to eight ($M = 4.45$, $SD = 1.72$).

Table 3

Percentage of Participants Experiencing Parkinson's Symptoms

Symptom	% Respondents experiencing symptom
Slowness of movement	84%
Stiffness	78%
Posture problems	40%
Tremor	81%
Problems initiating movement	31%
Muscle weakness	53%
Speech problems	43%
Problems with facial expression	32%

The average length of diagnosis was just over four years ($M = 4.11$, $SD = 2.88$) whereas the average time that participants reported believing to have had symptoms was over seven years ($M = 7.26$, $SD = 4.21$). The majority of respondents reported experiencing no other medical conditions (72%). Those with other conditions were not

excluded as questions were worded with particular reference to the effects of Parkinson's. The means and standard deviations for scales used in this study are shown in Table 4.

Table 4
Means, Standard Deviations, and Theoretical Range for work related psychosocial variables (N = 116)

Variable	<i>M(SD)</i>	Theoretical Range
Fatigue	44.42 (12.40)	9 - 63
Depression	5.66 (4.86)	0 - 21
Job Demand	7.01 (1.82)	2 - 10
Job Control	37.49 (9.45)	10 - 50
Employer Social Support	7.97 (5.97)	0 - 16
Colleague Social Support	9.44 (4.59)	0 - 16
Family and friends Social Support	13.39 (2.98)	0 - 16
Negative Social Support	20.07 (8.11)	13 - 52
Self-efficacy	31.70 (5.24)	10 - 40
QoL	26.76 (8.39)	7 - 49

Participants reported on average a high level of fatigue ($M = 44.42$). Sixty-five percent of respondents reported levels of fatigue that are regarded as significant for PWP (Herlofson & Larsen, 2002). Participants' level of depression ranged from normal to severe. The mean depression score was in the mild range and only 23% of respondents reported experiencing depression, whether it be mild or severe. In relation

to job control, participants reported having on average moderate levels to quite a lot of control over their work. Scores for work related social support indicated that participants reported receiving most positive support from family and friends and least support from their employers. It is important to note that, although positive social support was divided according to the source from which it was received, the measure for negative social support relates to negative social support from all people at work. On average, people at work were reported as rarely or never responding to participants in a way that they perceived as negative (through withdrawal or criticism). Participants reported a mean level of self-efficacy that fell in the average range indicating that they felt moderately able to deal with life's problems.

In relation to QoL, respondents reported a level that was a little less than moderately satisfying. The most satisfying dimension of participants' lives was family-life and experiences and the least satisfying dimension was intimacy and sexual experiences. However, the mean on all dimensions fell approximately within the moderately satisfying range.

In order to assess the influence of gender and level of education on QoL and depression a multiple analysis of variance (MANOVA) was conducted. MANOVA was also used to rule out any influence that disclosure to employers, hours of work (e.g. full-time vs. part-time) or a job that involves public speaking might have on QoL and depression.

There was no significant multivariate effect of gender on QoL and depression (Wilks' Lambada = .98, $F(2, 113) = .89, p > .05, \eta^2 = .02$). There was no significant multivariate effect of level of education on QoL and depression (Wilks' Lambada = .10, $F(10, 218) = .94, p > .05, \eta^2 = .04$). There was no significant multivariate effect of disclosure to an employer on QoL and depression (Wilks' Lambada = .96, $F(6, 222) = .77, p > .05, \eta^2 = .02$). There was no significant multivariate effect of hours of work (full-time or part-time) on QoL and depression (Wilks' Lambada = .10, $F(2, 113) = .13, p > .05, \eta^2 = .00$). There was no significant effect of whether a job involved public speaking or not on QoL and depression (Wilks' Lambada = .95, $F(4, 224) = .95, p > .05, \eta^2 = .03$). As these independent variables were not significant the data set was combined for further analyses.

6.3.3. *Hypothesis one*

Hypothesis one was tested by analysis of correlations between QoL and depression, and age, Parkinson's severity, Parkinson's duration, fatigue, job demands, job control, positive social support, negative social support and self-efficacy (see Table 5). Job control, support from family and friends and self-efficacy had a significant positive relationship with QoL and a significant negative relationship with depression. Parkinson's severity, fatigue and negative social support had a significant negative relationship with QoL and a significant positive relationship with depression. Job demands also demonstrated a significant positive relationship with depression.

These results indicate that those PWP who experience more severe symptoms, higher levels of fatigue, and are subject to incidents of negative social support, are likely to have a worse QoL and higher rates of depression than those PWP who do not. In contrast, those with higher levels of job control at work, more support from family and friends and high levels of self-efficacy are likely to experience a better QoL and lower levels of depression. PWP with jobs that are perceived as more demanding are more likely to experience depression but job demands do not influence QoL. As there were no significant relationships between age, Parkinson's duration, and any of the other variables, these variables were excluded from further analyses. Although social support received from employers and colleagues was not associated with either QoL or depression, there were significant relationships between these two variables and between support from employers and support from family and friends. All positive social support independent variables were therefore retained for further analyses.

Table 5

Correlations Between Demographic, Illness Related, Psychosocial, Work Related and Quality of Life Variables (N = 116)

	<i>QoL</i>	<i>Depression</i>	<i>Age</i>	<i>Severity</i>	<i>Duration</i>	<i>Fatigue</i>	<i>Job demands</i>	<i>Job control</i>	<i>Employer social support</i>	<i>Colleague social support</i>	<i>Family social support</i>	<i>Negative social support</i>
<i>Depression</i>	-.45**											
<i>Age</i>	.12	-.09										
<i>Parkinson's severity</i>	-.21*	.26**	-.15									
<i>Parkinson's duration</i>	.03	-.03	.37	.11								
<i>Fatigue</i>	-.29**	.37**	-.06	.41**	.06							
<i>Job demands</i>	-.14	.29**	-.07	.24**	-.01	.35**						
<i>Job control</i>	.20*	-.20*	.14	-.08	.10	-.22*	.09					
<i>Employer social support</i>	-.11	.03	-.08	.06	-.18	.13	.02	-.12				
<i>Colleague social support</i>	.02	-.17	.10	.05	.12	.13	.10	.12	.53**			
<i>Family social support</i>	.29**	-.28**	.05	-.06	.01	.07	-.05	.26**	.25**			
<i>Negative social support</i>	-.26**	.35**	.02	.16	.04	.35**	.05	-.28**	.00	-.22		
<i>Self-efficacy</i>	.32**	-.43**	.08	-.11	.03	-.22*	-.02	.38**	-.08	.03	.22*	-.16

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

6.3.4. Hypothesis two

The second hypothesis was that (after controlling for Parkinson's severity, Parkinson's duration, fatigue, age, gender and education) the construct of job demands, job control, positive social support (support from employers, colleagues and family and friends), negative social support and self-efficacy would predict QoL and depression in PWP in employment. This hypothesis was based on a version of the JSM adapted to PWP in the workplace. Data was analysed using a hierarchical regression. As outlined previously, age, gender, education and Parkinson's duration were not included in this analysis as their relationship with QoL and depression or other independent variables was not significant. Parkinson's severity and fatigue were entered at the first stage, and job demands, job control, social support from employers, colleagues and family and friends and negative social support and self-efficacy were entered at the second stage.

Using QoL as an outcome variable, the model was significant at both stages. Stage One explained 9.2% of the variance in QoL ($F(2, 113) = 5.74, p < .05$). At this stage, fatigue was a significant predictor of QoL but Parkinson's severity was not. At the second stage an additional 15.7% of the variance was explained ($F(7,106) = 3.16, p < .05$). After controlling for the influence of Parkinson's severity and fatigue, social support from family and friends and self-efficacy were significant predictors of QoL, but job demands, job control, social support from employers and colleagues and negative social support were not. This indicates that PWP who have high levels of positive support from family and friends and high levels of self-efficacy experience a better QoL. However, the level of demands that a job imposes on a PWP, the amount of control that they have over their work, positive support from employers and colleagues or incidences of negative social interaction do not significantly influence QoL. Fatigue was no longer significant at Stage Two, indicating that the contribution of fatigue at the first stage may have been accounted for by independent variables entered in Stage Two with which fatigue was associated (e.g. job demands, job control, negative social support and self-efficacy). The second hypothesis and the application of the JSM to PWP was therefore not supported when using QoL as a measure of job strain. Results of this analysis are shown in Table 6.

Table 6

*Hierarchical Regression Table of Factors Contributing to QoL of PWP in Employment
(N = 116)*

	<i>B</i>	SEB	<i>Beta</i>	<i>t</i>	Sig.
<i>Stage One</i>					
Severity	-.56	.48	-.12	-1.18	.24
Fatigue	-.16	.07	-.24	-2.42	.02
<i>Stage Two</i>					
Severity	-.45	.45	-.09	-.99	.32
Fatigue	-.11	.07	-.16	-1.49	.14
Job Demands	-.15	.43	-.03	-.34	.74
Job Control	-.03	.09	-.03	.33	.74
Social Support Employers	-.17	.14	-.12	-1.19	.24
Social Support Colleagues	-.05	.20	-.03	-.27	.79
Social Support Family & Friends	.80	.28	.28	2.84	.01
Negative Social Support	-.12	.10	-.12	-1.20	.23
Self-efficacy	.31	.15	.19	2.07	.04

This same analysis was repeated with depression as the outcome variable representing job strain in place of QoL. This model was also significant at both stages (see Table 7).

Table 7

Hierarchical Regression Table of Factors Contributing to Depression of PWP in Employment (N = 116)

	<i>B</i>	<i>SEB</i>	<i>Beta</i>	<i>t</i>	<i>Sig.</i>
<i>Stage One</i>					
Severity	.37	.27	.13	1.41	.16
Fatigue	.13	.04	.32	3.38	.00
<i>Stage Two</i>					
Severity	.31	.23	.11	1.31	.19
Fatigue	.07	.04	.17	1.78	.08
Job Demands	.50	.22	.19	2.24	.03
Job Control	.04	.05	.08	.90	.37
Social Support Employer	.09	.07	.11	1.18	.24
Social Support Colleagues	-.19	.11	-.18	-1.81	.07
Social Support Family & Friends	-.24	.15	-.15	-1.66	.10
Negative Social Support	.10	.05	.16	1.89	.06
Self-Efficacy	-.31	.08	-.33	-4.01	.00

Stage One (independent variables severity and fatigue) explained 15.5% of the variance in depression ($F(2, 113) = 10.36, p < .05$). Only fatigue was a significant predictor of depression. Stage Two of the model explained 40.5% of the variance in depression ($F(7, 106) = 6.35, p < .05$). Job demands and self-efficacy emerged as the only significant predictors of depression at this stage. Fatigue was no longer a significant predictor of depression at Stage Two. This indicates that PWP in the workplace were more likely to be depressed if they perceived their jobs to be highly demanding and had low levels of self-efficacy. The amount of control that PWP have over their work and positive and negative social support, however, do not appear to influence their mood state. The second hypothesis was therefore partially support since only job demands and self-efficacy were significant predictors of depression. Since neither job control nor any of the social support independent variables were predictors of depression, this model of the JSM was not applicable to PWP in the workplace.

6.3.5 Hypothesis three

The third hypothesis related to the role of job control and social support in moderating the effects of job demand on job strain. This hypothesis was tested using job control, employer social support, colleagues social support, family and friends social support and negative social support as potential moderators of job demands using, firstly, QoL as the dependent variable and, secondly, depression. The influence of Parkinson's severity and fatigue was controlled for in the analyses. Hierarchical regressions were used to test for moderating effects of job control and the various forms of social support.

Analysis for moderating effects of job control and negative social support on job demands using QoL as the dependent variable:

Before performing hierarchical regressions, independent variables were centred and interaction terms calculated as recommended by Aiken and West (1991). Parkinson's severity and fatigue were entered in Stage One in order to control for these variables. The other independent variables (job demands, job control, employer social support, colleagues social support, family and friends social support and negative social support) were entered in Stage Two, followed by the terms of interaction between job demands, and job control and social support variables in Stage Three, in order to assess the significance of the independent variables alone and then with the interaction terms (Aiken & West, 1991).

As can be seen from Table 8, a three-stage hierarchical regression was conducted to predict QoL. Stage One was significant and explained 9.2% of the variance predicting QoL ($F(2, 113) = 5.74, p < .05$). Only fatigue was a significant predictor. The second stage (all independent variables) explained 21.8% of the variance predicting QoL and was significant ($F(6, 107) = 2.88, p < .05$). At this second stage, family and friends social support was the only significant predictor of QoL. The third stage of the hierarchical regression was found to account for 22.6% of the variance predicting QoL. The explanation of an additional .8% of variance in QoL was not significant ($F(5, 102) = .20, p > .05$). No significant moderating interactions were identified. Job control and the various forms of social support did not therefore moderate the relationship between job demands and QoL.

Table 8.

Three Stage Hierarchical Regression Testing for the Interaction Effect of Job Demands, Job Control and Social Support on QoL (N = 116)

	<i>B</i>	<i>SEB</i>	<i>Beta</i>	<i>t</i>	<i>Sig.</i>
<i>Stage One</i>					
Parkinson's severity	-.56	.47	-.12	-1.18	.24
Fatigue	-.16	.07	-.24	-.24	.02
<i>Stage Two</i>					
Parkinson's severity	-.47	.46	-.10	-1.03	.31
Fatigue	-.13	.07	-.19	-1.78	.08
Job demands (centred)	-.11	.44	-.03	-.26	.80
Job control (centred)	.02	.09	.02	.25	.80
Employer social support (centred)	-.18	.15	-.13	-1.25	.21
Colleague social support (centred)	-.07	.21	-.04	-.34	.73
Family & friends social support (centred)	.90	.28	.32	3.21	.00
Negative Social Support (centred)	-.16	.10	-.16	-1.61	.11
<i>Stage Three</i>					
Parkinson's severity	-.63	.48	-.13	-1.30	.20
Fatigue	-.06	.08	-.08	-.74	.46
Job demands (centred)	-.30	.47	-.06	-.63	.52
Job control (centred)	.12	.08	.13	1.40	.17
Employer social support (centred)	-.16	.15	-.12	-1.07	.29
Colleague social support (centred)	-.07	.22	-.04	-.33	.74
Family & Friends social support (centred)	.84	.31	.30	2.74	.01
Negative social support (centred)	-.12	.11	-.12	-1.15	.25
Job demands x job control (centred)	-.03	.05	-.06	-.61	.54
Job demands x employer social support (centred)	.00	.08	.00	-.04	.97
Job demands x colleagues social support (centred)	.00	.10	.00	.01	.99
Job demands x family & friends social support (centred)	-.07	.16	-.05	-.43	.67
Job demands x negative social support (centred)	.00	.05	-.00	-.01	.10

Analysis for moderating effects of job control and negative social support on job demands using depression as the dependent variable

As shown in Table 9 a three-stage hierarchical regression was performed to predict depression. Parkinson's severity and fatigue were entered at the Stage One. Job demands, job control, employer social support, colleague social support, family and friends social support and negative social support were entered at the Stage Two. To test for moderation, the independent terms of job demands and the other independent variables were entered at Stage Three.

Stage One was significant and accounted for 15.5% of the variance predicting depression ($F(2, 113) = 10.37, p < .05$) and only fatigue was a significant predictor. Stage Two accounted for 31.4% of the variance predicting depression. The additional 15.9% of variance explained by Stage Two was significant ($F(6, 107) = 4.15, p < .05$). At the second stage only fatigue and family and friends social support were significant predictors of depression. Stage Three of the hierarchical regression accounted for 32.5% of the variance predicting depression. The explanation of an additional 1.1% of variance at the third stage was not significant ($F(5, 102) = .31, p > .05$). Fatigue was the only significant predictor of depression, although family and friends social support displayed marginal significance ($p = .05$). No significant moderating interactions were identified. Job control and the various forms of social support did not therefore moderate the relationship between job demands and depression.

Table 9.

Three Stage Hierarchical Regression Testing for the Interaction Effect of Job Demands, Job Control and Negative Social Support on Depression (N = 116)

	<i>B</i>	<i>SEB</i>	<i>Beta</i>	<i>t</i>	<i>Sig.</i>
<i>Stage One</i>					
Parkinson's severity	.38	.27	.13	1.41	.16
Fatigue	.13	.04	.32	3.40	.00
<i>Stage Two</i>					
Parkinson's severity	.33	.25	.12	1.31	.19
Fatigue	.09	.04	.22	2.22	.03
Job demands (centred)	.47	.23	.18	1.97	.05
Job control (centred)	-.01	.05	-.02	-.20	.84
Employer social support (centred)	.10	.08	.12	1.25	.22
Colleagues social support (centred)	-.17	.11	-.16	-1.55	.15
Family & friends social support (centred)	-.34	.15	-.21	-2.25	.03
Negative social support (centred)	.10	.06	.16	1.77	.08
<i>Stage Three</i>					
Parkinson's severity	.29	.26	.10	1.14	.26
Fatigue	.09	.04	.24	2.25	.03
Job demands (centred)	.47	.25	.18	1.87	.07
Job control (centred)	.00	.05	-.01	-.08	.94
Employer social support (centred)	.10	.08	.13	1.26	.21
Colleagues social support (centred)	-.18	.12	-.17	-1.57	.12
Family & friends social support (centred)	-.33	.17	-.20	-2.00	.05
Negative social support (centred)	.10	.06	.17	1.77	.08
Job demands x job control (centred)	.01	.03	.02	.18	.86
Job demands x employer social support (centred)	-.02	.05	-.03	-.34	.74
Job demands x colleagues social support (centred)	-.03	.05	-.06	-.52	.61
Job demands x family & friends Social support (centred)	.09	.09	.03	.31	.75
Job demands x negative social support (centred)	.03	.03	.08	.84	.40

Since the addition of the interactions did not significantly vary the amount of variance explained in either QoL or depression, hypothesis three was not supported. Job control and all types of social support did not moderate the effect of job demands on either QoL or depression.

6.3.5. *Hypothesis four*

The fourth hypothesis related to the role of self-efficacy in moderating the effects of both job demands and job control on QoL and depression. This hypothesis was tested, firstly, with QoL as the dependent variable and, secondly, with depression as the dependent variable. Parkinson's severity and fatigue were entered in Stage One of the hierarchical regression to control for these variables. In order to test for an interaction effect the independent variables were centred and their interaction terms calculated. For each hierarchical regression, the independent variables were entered in Stage Two, followed by the inclusion of their interaction terms at the third stage in order to assess the significance of the independent variables alone and then with the interaction terms (Aiken & West, 1991).

Analysis for moderating effects of self-efficacy on job demands and job control using QoL as the dependent variable:

As shown in Table 10, a three-stage hierarchical regression was conducted to predict QoL. Parkinson's severity and fatigue were entered at the Stage One. Job demands, job control and self-efficacy were entered at Stage Two. To test for moderation, these variables and their interaction terms were entered at Stage Three. Stage One was significant and accounted for 9.2% of the variance predicting QoL ($F(2, 113) = 5.74, p < .05$). Stage Two explained 16.6% of the variance predicting QoL. The explanation of an additional 7.4% of variance in QoL at the second stage was significant ($F(3, 110) = 3.25, p < .05$). At this second stage only self-efficacy was a significant predictor of QoL. The third stage of the hierarchical regression was found to account for 18.7% of the variance predicting QoL. The explanation of an additional 2.1% of the variance predicting QoL was not significant ($F(3, 107) = .93, p = .43$). Again only self-efficacy was a significant predictor of QoL. No significant moderating interactions were identified. Self-efficacy did not therefore moderate the relationships between job demands, job control and QoL.

Table 10.

Three Stage Hierarchical Regression Testing for the Interaction Effect of Self-Efficacy, Job Demands and Job Control on QoL (N = 116)

	<i>B</i>	<i>SEB</i>	<i>Beta</i>	<i>t</i>	<i>Sig.</i>
<i>Stage One</i>					
Parkinson's severity	-.56	.47	-.12	-1.18	.24
Fatigue	-.16	.07	-.24	-.24	.02
<i>Stage Two</i>					
Parkinson's severity	-.50	.47	-.10	-1.06	.29
Fatigue	-.11	.07	-.16	1.62	.11
Job demands (centred)	-.25	.43	-.05	-.58	.57
Self-efficacy (centred)	.43	.14	.27	3.02	.00
<i>Stage Three</i>					
Parkinson's severity	-.55	.47	-.11	-1.18	.24
Fatigue	-.11	.07	-.17	-1.66	.10
Job demands (centred)	-.19	.43	-.04	-.45	.66
Self-efficacy (centred)	.43	.14	.27	3.02	.00
Job demands x self-efficacy (centred)	-.09	.08	.09	1.07	.29
Job control x self-efficacy (centred)	.02	.02	.12	1.31	.19
Job demands x job control x self-efficacy (centred)	-.00	.01	-.02	-.17	.86

Analysis for moderating effects of self-efficacy on job demand and job control using depression as the dependent variable:

As shown in Table 11, a three stage hierarchical regression was conducted to predict depression. Parkinson's severity and fatigue were entered at Stage One. Job demands, job control and self-efficacy were entered at Stage Two. To test for moderation, these variables and their interaction terms were entered at Stage Three. Stage One explained 15.5% of the variance in predicting depression and was significant ($F(2, 113) = 10.37, p < .05$). At the first stage only fatigue was a significant predictor.

The second stage explained 31.3% of the variance predicting depression. The explanation of an additional 15.8% of the variance in depression at Stage Two was significant ($F(3, 110) = 8.28, p < .05$). At this second stage job demands and self-efficacy were significant predictors of depression. The third stage of the hierarchical regression was found to account for 34.6% of the variance predicting depression. The explanation of an additional 3.3% of the variance predicting depression was not significant ($F(3, 107) = 1.95, p = .13$). Job demands and self-efficacy were again significant predictors of depression. The interaction of self-efficacy and job demands on depression was significant indicating that self-efficacy did moderate the relationship between job demands and depression.

Table 11.

Three stage hierarchical regression testing for the interaction effect of self-efficacy, job demands and job control on depression (N = 116)

	<i>B</i>	<i>SEB</i>	<i>Beta</i>	<i>t</i>	<i>Sig.</i>
<i>Stage One</i>					
Parkinson's severity	.38	.27	.13	1.41	.16
Fatigue	.13	.04	.32	3.38	.00
<i>Stage Two</i>					
Parkinson's severity	.29	.25	.10	1.16	.25
Fatigue	.07	.04	.18	1.89	.06
Job demands (centred)	.52	.23	.19	2.24	.03
Job control (centred)	-.01	.05	-.03	-.31	.76
Self-efficacy (centred)	-.34	.08	-.37	-4.22	.00
<i>Stage Three</i>					
Parkinson's severity	.21	.25	.08	.86	.39
Fatigue	.07	.04	.17	1.80	.07
Job demands (centred)	.56	.25	.21	2.22	.03
Job control (centred)	-.02	.05	-.04	-.51	.61
Self-efficacy (centred)	-.33	.08	-.36	-4.12	.00
Job demands x self- Efficacy (centred)	-.09	.05	-.18	-2.01	.05
Job control x self-efficacy (centred)	.00	.01	.01	.11	.91
Job demands x job control x self-efficacy (centred)	.00	.01	.04	.37	.71

Figure 4 shows the interaction between job demands and self-efficacy.

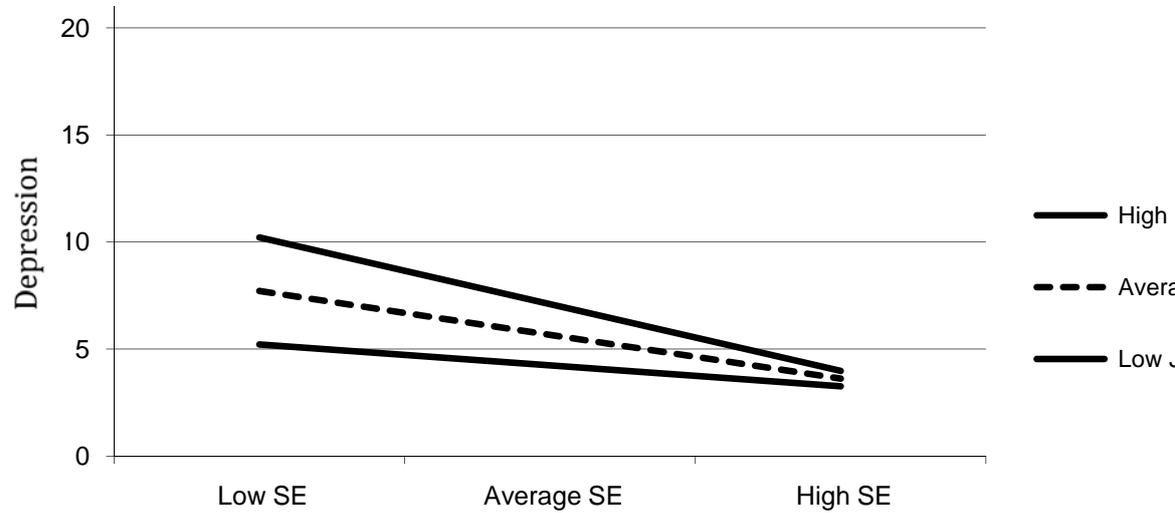


Figure 4. Perceived Job Demands by Self-efficacy by Depression
Note. JD = Job Demands SE – Self-efficacy

As shown in Figure 4, low self-efficacy in PWP was associated with higher levels of depression, as were high levels of job demands. Irrespective of the level of job demands, PWP who reported high self-efficacy reported the lowest levels of depression. PWP with high job demands were less likely to experience depression if they had a high level of self-efficacy. Self-efficacy therefore plays an important role in prevention of the development of depression in PWP in employment.

The hypothesis in relation to the moderating influence of self-efficacy on the relationship between both job demands and job control, and QoL and depression was only partially supported. Self-efficacy moderated the relationship between job demands and depression but no such effect was found in relation to QoL.

The aim of Stage Two of this research was to establish quantitatively the psychosocial work-related factors that influence the QoL and depression of PWP in employment within a framework of the JSM. Results will be discussed firstly in relation to the four hypotheses, followed by a review of the implications of these results in terms of the application of the JSM to the work experience of PWP.

6.4.1 *Hypothesis one*

The first hypothesis related to relationships between the independent and dependent variables. It was hypothesised that job control, positive social support and self-efficacy in PWP in employment would be positively related to QoL, and that Parkinson's severity, fatigue, job demands and negative social support would be negatively related to QoL. It was also hypothesised that fatigue, job demands and negative social support would be positively related to depression, and that Parkinson's duration, job control, positive social support and self-efficacy would be negatively related to depression. Parkinson's duration was expected to be unrelated to either QoL or depression.

The first hypothesis was partially supported in respect of the relationships between all independent variables and QoL and depression, with the exception of job demands and positive social support from employers and colleagues. People with more severe Parkinson's tended to have a worse QoL and more depression than those with less severe symptoms. This supports previous findings that QoL and depression in PWP are related to a progression in the illness (Koplas et al., 1999; Kuopio et al., 2000; Schrag et al., 2000; Slawek et al., 2005) and contradicts Behari et al.'s (2005) findings that the high levels of medication required to maintain employment as Parkinson's progresses have a negative effect on QoL. In support of Caap-Ahlgren and Dehlin (2001), Herlofson and Larsen (2003) and Scaravelli (2003), higher levels of fatigue in PWP were associated with worse QoL and higher rates of depression. Consistent with previous research, Parkinson's duration, or the length of time since diagnosis, was not related to either QoL (Behari et al, 2005; Kuopio et al., 2000; Schrag, 2006) or depression (MacCarthy & Brown, 1989; McQuillen & Licht, 2003; Rao et al., 1992).

In relation to the work specific constructs that form the principal components of the JSM, higher levels of job control were associated with better QoL and lower rates of depression, consistent with previous findings examining the model's application to

healthy workers (Karasek, 1979; Sparks & Cooper, 1999; Van der Doer & Maes, 1999; Wallace, 2005). Findings in relation to job demands, however, were not as expected. Although increased job demands were associated with higher rates of depression as has previously been found (Karasek, 1979; Karasek et al., 1982; Van der Doef & Maes, 1999), no such association was found between job demands and QoL. Since both QoL and depression were used in this study to measure job strain, these results indicate that job strain may be better represented by a measure of depression than by a measure of QoL.

Positive social support from family and friends in relation to work was associated with both QoL or depression. This supports previous findings (Karasek et al., 1982; Noblet & Rodwell, 2009; Vanroelen et al., 2009) who found that social support assisted to maintain well-being of healthy workers and was therefore a valid component of the JSM. However, these findings are challenged by current results indicating that positive support from employers and colleagues was not associated with a better QoL and less depression. These conflicting findings in relation to different sources of positive social support confirm Wallace's (2005) similar results. Wallace found that social support emanating from different sources (e.g., employer, colleague, spouse) had different effects on worker well-being. The role that positive social support plays in the JSM and its composition requires further investigation.

The first hypothesis was supported in relation to negative social support and self-efficacy, the concepts added to the JSM to make it more appropriate to PWP. Negative social support in relation to work was associated with a worse QoL and higher rates of depression, consistent with findings in relation to people living with chronic illness (Ray, 1992; Revenson, 1991; Norton et al., 2005). In relation to this first hypothesis, PWP with high levels of self-efficacy were found to have a better QoL and less depression than those with low levels of self-efficacy. This confirms the positive outcomes associated with being able to address work related issues due to high levels of self-efficacy (Fujii et al., 1997; Tsaousides et al., 2009).

6.4.2 *Hypothesis two*

The second hypothesis was designed to test the JSM for PWP and predicted that (after controlling for Parkinson's severity and duration, fatigue, age, gender and education) the constructs of job demands, job control, positive social support, negative social support and self-efficacy would predict QoL and depression in PWP in

employment. This hypothesis was partially supported, indicating that the JSM in the form used in this study is not applicable to PWP in employment.

Only self-efficacy and positive support received from family and friends predicted QoL and only job demands, negative social support and self-efficacy predicted depression. This finding is in contrast to previous research validating the use of the JSM to explain well-being in the workplace (Karasek et al., 1981; Van der Doef & Maes, 1999) whereby job demands and job control form essential components of the model. However, this result validates findings from Stage One of this project which indicated that self-efficacy and negative social support played a valuable role in explaining the workplace experience of PWP and could be potential additional components of the JSM. Using depression as a measure of job strain, this result also confirms previous findings of Lincoln (2000) that negative social support influenced psychological well-being more than positive social support.

In relation to self-efficacy, results are consistent with Varekamp et al. (2006), who established that self-efficacy influences the work experience of chronically ill populations. According to the current model, once self-efficacy is taken into account, job control no longer predicts job strain. This reflects the significant positive relationship between self-efficacy and job control and is consistent with Jimmieson (2000) and Schaubroeck and Merritt (1997). This indicates that self-efficacy may be of particular importance to vulnerable populations such as PWP in dealing with difficulties at work and its role therefore requires further investigation.

Since neither of the principal components of the JSM (job demands and job control) were predictors of QoL, but job demands did predict depression, depression appears a more appropriate measure of job strain for future research. The failure of any form of social support to predict depression conflicts with previous findings (Gignac, 2005; Koch et al., 2005; Lidal et al., 2007; Patel et al., 2007) but is consistent with Noblet and Rodwell (2009), Vanroelen et al., (2009) and Wallace (2005) who found that the influence of positive social support on well-being of people in the workplace was dependent on the type and source of that support. It is possible that consistently above average levels of positive social support may mask the effect of support on well-being. Extremely low levels of positive social support (e.g., an isolated PWP with no family or friends) may have been subject to different effects. Although the role of positive social support from family and friends predicts QoL in PWP, perhaps its

influence is more to do with support provided 24 hours a day rather than support that relates specifically to workplace difficulties.

6.4.3. *Hypothesis three*

The third hypothesis stated that, after controlling for Parkinson's severity, Parkinson's duration and fatigue, job control, positive social support and negative social support, would moderate the effect of job demands on QoL and depression in PWP. This hypothesis was not supported as no moderating effects were found. In contrast to Van der Doef and Maes (1999), job control and social support from employers, colleagues and family and friends did not buffer the effects of job demands on QoL or depression in PWP. Furthermore, negative social support did not exacerbate the effects of job demands on QoL or depression. This finding was in contrast to Stage One of this project that found that negative social support at work had a detrimental effect on how PWP experienced work. This indicates that the influence of job demands in increasing rates of depression cannot be reduced by interventions aimed at increasing the control that an employee has over their work, by increasing positive social support, or by reducing incidences of negative social interaction for PWP in the workplace.

6.4.4. *Hypothesis four*

The fourth and final hypothesis tested the moderating effects of self-efficacy on job demands and job control in PWP in the workplace. This hypothesis was partially supported. Self-efficacy was found to moderate the effect of job demands on depression but had no such effect when QoL was used as a measure of job strain. Self-efficacy did not, however, moderate the effect of job control on job strain. The result in relation to the interaction between job demands and self-efficacy and its effect on depression is consistent with previous research into the benefits of self-efficacy in terms of helping maintain employment for people with chronic illness (Roessler & Rumrill, 1994; Tsaousides et al., 2009).

PWP with high levels of self-efficacy were less likely to be subject to the depressive effect of high job demands than those with low levels of self-efficacy. This indicates that, rather than reducing job demands in order to accommodate Parkinson's, interventions that promote self-efficacy are likely to assist PWP in meeting those demands and thereby deter depression. This in turn is likely to mean PWP feel able to remain in employment for longer, thereby maintaining their QoL. This conclusion is

consistent with the JSM that asserts that a reduction in job demands can make a previously engaging job become boring and increase the likelihood of an employee becoming disengaged from their work (Karasek, 1979).

6.4.5. *The JSM*

Although the hypotheses were not fully supported, this adapted version of the JSM emerged as useful in explaining the psychological well-being of PWP in the workplace. In support of the JSM for PWP, job demands, job control, positive social support from family and friends, negative social support and self-efficacy were related to QoL and depression. However, once fatigue and Parkinson's severity were taken into account, only positive social support from family and friends and self-efficacy were predictive of QoL, and only job demands and self-efficacy were predictive of depression. There are several possible explanations for this.

Firstly, these findings demonstrate significant correlations between some constructs measured that would have affected outcomes. For instance, the relationship between job demands and both fatigue and Parkinson's severity means that, once these latter two constructs were taken into account, the influence of job demands on job strain was diminished and, in the case of QoL, was no longer significant. Similarly, the relationships between job control and fatigue, positive support from friends and family, and self-efficacy mean that, once fatigue was controlled for, positive support from family and friends and self-efficacy accounted for a considerable proportion of the relationship between job control and QoL. Any predictive value of job control on QoL therefore became non-significant. Likewise, in terms of depression, the predictive value of self-efficacy accounted for a considerable proportion of the relationship between job control and positive support from family and friends and psychological well-being. In order to counteract this, future research needs to try to find or develop measures that are able to more clearly distinguish between the various concepts.

Secondly, the relationship between Parkinson's, employment and fatigue is not clear. In this study fatigue was viewed as symptomatic of Parkinson's. However, fatigue may occur as a result of Parkinson's rather than as a symptom, and the relationship between job demands and fatigue may mean that some of this fatigue occurs purely as a result of working. If fatigue were viewed as resulting from the combined effects of Parkinson's and the demands of work, it would necessarily become an outcome variable in the analysis, and different results might have been forthcoming.

In the original JSM (Karasek, 1979) the experience of exhaustion formed part of the definition of job strain. It may be that the investigation of the workplace experience using the JSM may be difficult with populations whose chronic condition itself brings about high levels of fatigue.

Thirdly, as with fatigue, the relationship between depression and Parkinson's is not fully understood. Depression emerges from this study as more representative of job strain than a measure of QoL. Indeed, the original JSM defined job strain as a psychological construct (e.g., depression) (Karasek, 1979) rather than a functional one (e.g. QoL). Although the association between depression and QoL is well established in PWP (Behar et al., 2005; Carol-Artal et al., 2008; Cubo et al., 2002; Kuopio et al., 2000; Reuther et al., 2007; Schrage, 2006; Slawek et al., 2005), the two constructs are not interchangeable and depression appears to more appropriately reflect job strain. Furthermore, the question remains as to whether depression occurs as a result of the interaction of Parkinson's with other environmental factors related to employment, or whether for some PWP, depression constitutes a symptom of the condition (Behari et al., 2005; Carol-Artal et al., 2008; Cubo et al., 2002; Kuopio et al., 2000; Reuther et al., 2007; Schrage, 2006; Slawek et al., 2005). Depending on which stance a researcher takes, the construct of depression takes the role of either independent or dependent variable in an exploratory model and results will differ accordingly. Further research is required in order to establish ways of distinguishing between depression as symptom of Parkinson's and depression that is a consequence of living with Parkinson's.

6.4.6. *Self-efficacy*

Self-efficacy emerged as the strongest predictor of depression in PWP in the workplace and therefore an important addition to a population-specific JSM. People with high levels of self-efficacy were less likely to experience depression. When other JSM variables were included in the regression equation, self-efficacy was one of only two independent predictors of QoL in this population. Furthermore, self-efficacy was the only factor that acted as a buffer against the effects of job demands on psychological well-being of PWP in the workplace. In other words, high levels of self-efficacy helped PWP to withstand the negative effects of high job demands on well-being. This is consistent with previous research using the JSM that has shown that self-efficacy can reduce the adverse impact of job demands on psychological health (Salanova et al., 2005). This also confirms previous research that self-efficacy plays a major role in

establishing and maintaining employment for people with chronic illness (Roessler & Rumrill, 1994; Tsaousides et al., 2009).

This finding has immense practical implications. Since self-efficacy training is effective for people with chronic illness in the workplace (Varekamp & van Dijk, 2006), self-efficacy training for people with Parkinson's in employment is likely to be beneficial in improving their psychological health and make it easier for them to remain in employment. Building confidence in skills to deal with work related problems could help people with Parkinson's to be proactive in obtaining the adjustments to their work role that are needed to improve their workplace experience. These skills could also be useful in taking control of the decision of when to leave work when the progression of Parkinson's means that staying in employment is no longer a viable choice.

6.4.7 *Negative social support*

Although negative social support was not a predictor of QoL or depression using this model, it was associated with both and therefore its introduction into the JSM for PWP was validated. PWP who experience more negative social interactions are more likely to have depression and a worse QoL than those who experience fewer such interactions. This clearly supports qualitative findings of the current study where PWP talked of distressing incidents where they felt that people at work had been less than supportive in relation to their health condition. It also confirms previous research findings that negative social support is associated with depression (Ray, 1992; Revenson, 1991; Norton et al., 2005).

The predominance of negative over positive social support in the current study in relation to psychological health confirms findings of Lincoln's (2000) review of studies into negative social support. PWP, as a vulnerable population, may be particularly sensitive to the effects of negative social interactions. On average, PWP rarely experienced incidents of negative reactions from others at work and yet it appears that these few incidents could have a profound impact on their well-being. This is in contrast to the relatively high levels of positive social support that they received from employers and colleagues that was not significantly associated with their psychological health. Further research into the effects of negative social support for PWP is warranted.

6.4.8. *Depression*

Less than a quarter of people surveyed reported experiencing depression, a result that conflicts with previous research indicating that an estimated 40% of people with Parkinson's experience depression (Dakof & Mendelsohn, 1986; Rao, Huber, & Bornstein, 1992). Rates of depression have previously been reported to be even higher in younger PWP (Calne et al., 2008) and results from the qualitative study of this project indicated that half of the participants experienced depression. There are several ways of explaining this discrepancy.

Firstly, it may be explained by the role that employment plays in improving the psychological well-being of PWP of working age (Klepac et al., 2008). Alternatively, if depression is viewed as a symptom of the illness itself, depression may prevent people from participating in the workforce, thus explaining the low rate of depression in the current sample. The direction of the relationship between depression and employment remains unclear and is beyond the scope of the current project. Finally, it should be noted that a measure of the experience of symptoms of depression such as the DASS-21 does not account for whether respondents are taking medication for depression or not. An individual may be living with depression but, due to the effectiveness of medication, not currently be experiencing symptoms. Nevertheless, for the purposes of assessing rates of depression amongst a particular population, an individual medicating for depression would need to be categorised as experiencing depression. Close attention needs therefore to be given to the methodology for assessing depression in non-clinical samples.

6.4.9. *Summary*

In summary, although the hypotheses in relation the JSM were not fully supported, this study provides ample evidence that the JSM could be further explored in terms of its efficacy in explaining the work experience of PWP. Depression is a more appropriate outcome variable than QoL and self-efficacy and negative social support were validated as important environmental factors in the work experience of PWP.

6.4.10. *Methodological limitations*

This study was cross-sectional in nature thereby limiting interpretation of results. A longitudinal and comparative study would be able to add further insight into the effect of work on the QoL and psychological health of PWP. This study was also limited by the difficulties of research involving small populations such as people living

with a particular chronic illness. In order to recruit sufficient participants for effective analysis, it was necessary to combine data from PWP in diverse types of employment. This meant that their work experiences may be very different and these differences may have confounded results.

The findings of this study are also necessarily affected by the demographic composition of the sample. As expected, the majority of PWP in employment had a high level of education, confirming previous research findings that people with chronic conditions are more likely to be in employment if they are well educated (Rumrill et al., 2004). Psychosocial research, where participation is voluntary, traditionally attracts a highly educated sample and in this current study PWP who were university educated and employed in professional or semi-professional occupations were overrepresented. Manual work was therefore underrepresented and the effects of physical demands on PWP may have been masked.

Well educated participants are likely to have high levels of self-efficacy and control over their work environments and be able to be proactive in productive relationships with health professionals in order to harness the information and support needed to make informed decisions about their employment. Those with more education may also be in a better financial position to access the support of allied health professionals such as physio, massage and speech therapists and participate in instruction in yoga and tai chi, that have both been found to be beneficial for some people with Parkinson's (Marjama-Lyons & Koller, 2001; Samii et al., 2004). This predominance of high education amongst the sample may therefore mask the effect of other constructs under investigation.

6.4.11. *Future research*

There are several directions for future research into PWP and the JSM. Firstly, it could focus on ensuring that the Parkinson's specific environmental constructs added to the model do not overlap with the principal components of the original model (e.g., job demands and job control). This objective could also be achieved by adapting measures for these original concepts to ensure that they are specifically relevant to PWP (e.g., incorporating self-efficacy into a measure of job control). Secondly, future research could investigate further the concept of negative social support in Parkinson's and its influence on QoL and depression. Finally, an intervention to promote self-

efficacy in younger PWP could be designed and evaluated to determine its efficacy in improving the employment experience.

CHAPTER SEVEN

GENERAL DISCUSSION

The aim of this research was to explore the experience of PWP in the workplace using both qualitative and quantitative approaches. In the light of limited Australian research in the area of Parkinson's and employment, Stage one comprised interviews with six Australian PWP who were either working or had just left the workforce. A grounded theory approach was used to explore the working lives of PWP, allowing predominant themes to be established from the interviewees' perspective. Stage Two focused on themes identified in Stage One and incorporated them into a version of the JSM (Karasek, 1982), adapted for PWP in order to identify the psychosocial factors that most influence the psychological well-being and QoL of this chronically ill population. One hundred and sixteen working Australians with Parkinson's (age $M = 53.61$ years) participated in an online survey designed to investigate the appropriateness of applying the JSM to the working lives of PWP. This discussion draws conclusions from results of both Stage One and Stage Two of this research.

The PWP interviewed talked of employment as vitally important to their lives in terms of contributing to a sense of purpose, providing mental stimulation and social contact. They identified fatigue, the demands of their jobs, the control they had over their work, social support (both positive and negative) and self-efficacy as the most important factors influencing their working lives. Hypotheses in relation to the adapted version of the JSM (incorporating negative social support and self-efficacy) were partially supported. Principal findings in relation to the model were that positive support received from family and friends and self-efficacy predicted QoL and job demands, negative social support and self-efficacy predicted depression, and that self-efficacy moderated the relationship between job demands and depression.

Rates of depression amongst the PWP surveyed for this research were lower than in a generic sample of PWP and were determined not by the severity of the condition, but by other psychosocial influences. Although fatigue was cited by interviewees to be one of the hardest things to deal with at work, and emerged as a predictor of depression in the quantitative data, many PWP were enduring high levels of fatigue whilst working.

The JSM provided a valuable framework for investigating the work experience of PWP. As one of the most influential factors affecting psychological health in PWP in employment, job demands are currently viewed as the easiest thing to change in order to reduce work related stress. This research indicates that awareness needs to be promoted in relation to the impact of both mental and social demands work as well as physical demands, in terms of their effect on psychological well-being of PWP. However, improving psychological health of employees with Parkinson's is not just a simple matter of reducing the demands of a work role. According to the JSM, taking this approach is likely to result in the PWP becoming disengaged from their job and vulnerable to depression.

Relieving PWP of some of the more challenging tasks of a job in order to reduce stress for an employee may create what Karasek (1979) described as a 'passive job' by taking away from the worker their sense of purpose. Such actions may have additional adverse effects if taken without consultation, leaving the PWP feeling overlooked and with a sense of loss of control. If employers were made aware of the impact of such actions on the employee with Parkinson's or other chronic conditions, they may be more ready to consider ways of adapting tasks in consultation with their employee in order to both retain the purpose of a role and ensure that the employee feels some sense of control over decisions affecting their job.

Alternatively, effective interventions to increase levels of self-efficacy would buffer the negative effects of job demands by allowing employees to find solutions to coping with high job demands. In this way they would maintain their interest in work, reducing the likelihood of developing depression and lengthening the time that they remain in employment post-diagnosis. This in turn is likely to have beneficial effects in terms of QoL.

Self-efficacy was also associated with job control and in this study self-efficacy accounted for the association between job control and psychological well-being. Control and loss of control are salient factors in the lives of PWP and the development and use of a measure of job control tailored specifically to people with chronic illness may enhance the effectiveness of the JSM in explaining their particular work experience. This should incorporate some of the work-related issues of control raised by PWP such as uncertainty about the future, medication, ability to attend medical appointments and the unpredictability of symptoms as well as a self-efficacy component, since maintaining control in the workplace for PWP appears to be having

the confidence to deal with the problems that the condition poses. The various aspects of control for PWP in the workplace need to be brought to the attention of their employers. Unless an employer is aware of the issues that accompany a Parkinson's diagnosis, they are unable to be of much assistance to their employee.

The impact of negative social interactions at work, even though infrequent, was reported by interviewees to be extremely distressing. These reports were validated by quantitative results indicating that negative social support predicted depression in PWP, but positive social support did not. In terms of workplace interventions, it appeared more important to reduce the occurrence of negative interactions than to increase positive social support. Although withdrawal behaviours may be prevented through education to promote positive social support, employers and colleagues could also benefit from education in relation to the potential for negative effects of well-intentioned social support. Employers and colleagues, through lack of education about a chronic condition, may make presumptions about what may be helpful, e.g., reducing job demand, as referred to earlier or withdraw due to fear of doing or saying the wrong thing. Educating the employees of an organisation about the health condition affecting one of their colleagues may be the first step towards opening dialogue that could reduce negative social interactions.

The significance of this research is multi-faceted. Firstly, this research is the first study of Parkinson's and employment that incorporates both qualitative and quantitative data and therefore is able to suggest meaning to the quantifiable results. The quantitative results not only consolidate qualitative findings of the current research but also add weight to previous Australian research on Parkinson's and employment (McCabe et al., 2008). This is one of the few studies examining the experience of PWP in the workplace in relation to psychological well-being and QoL. Secondly, this is the first study using the JSM to help to understand the work experience of PWP. Thirdly this is one of the few psychosocial studies of younger PWP and the first research in Australia to use a sample of PWP who are all currently working. As such, although it may have relevance to a minority of people living with this condition, its implications are fundamental to the daily lives of this sector of the Parkinson's community and are largely neglected in existing research. Fourthly, this study has revived the concept of negative social support as an important component in terms of its association with QoL and psychological well-being in people living with chronic conditions. Finally, the

findings of this study are relevant not only to PWP but perhaps also to other chronically ill populations or vulnerable employees (e.g., pregnant women and the aged).

Several recommendations can be posited from the results of this research.

(1) PWP themselves need to be able to access education and self-efficacy training in relation to how Parkinson's is likely to affect their work and how to go about managing this. (2) employers and colleagues need to be informed, perhaps by Parkinson's 'advocates', about what a diagnosis means in terms of work for their employee and how they can best assist. This includes maintaining regular communication and consultation with their chronically ill employee in order to remain up to date with the challenges presented by the progression of the condition, and being made aware of the dangers of reducing the demands of a job, thereby making it 'passive'. (3) health professionals need to be alerted to the need to consider employment related issues when treating PWP if they are still in employment. This constitutes part of health professionals taking a holistic view of the condition rather than seeing it as a set of medical symptoms that need to be treated. Assisting PWP in maintaining employment, should they wish to do so, is likely also to assist them in maintaining good psychological health and QoL.

Although Parkinson's has its own specific set of symptoms and psychosocial consequences, many of the above findings may have relevance to other chronic conditions. Perhaps the JSM could be used to investigate the experience of people with MS and HIV-AIDS in the workplace. By careful choice of measures and the addition of environmental factors relevant to a particular health population, the JSM could be useful in helping to improve the working lives of individuals managing a wide range of conditions. As with other chronic conditions, assisting PWP to maintain work makes financial sense for the economy as a whole. By bringing focus to this subject, Parkinson's may be included more frequently on the list of chronic conditions affecting people of working age. Without this, PWP find themselves with little assistance in facing the daily challenges of managing their condition whilst maintaining employment. For PWP of working age, loss of employment can have devastating personal, financial and psycho-social consequences that to date have been rarely acknowledged.

References

- Aberg, F., Rissanen, A.M., Sintonen, H., Roine, R.P., Hockerstedt, K., & Isoniemi, H. (2009). Health-related quality of life and employment status of liver transplant patients. *Liver Transplantation, 15*, 64-72.
- Aboa-Eboule, C., Brisson, C., Maunsell, E., Masse, B., Bourbonnais, R., Vezina, M., Milot, A., Theroux, P., & Dagenais, G.R. (2007). Job strain and risk of acute recurrent coronary heart disease events. *Jama-Journal of the American Medical Association, 298*, 1652-1660.
- Abudi, S., Bar-Tal, Y., Ziv, L., & Fish, M. (1997). Parkinson's disease symptoms - patients' perceptions. *Journal of Advanced Nursing, 25*, 54-59.
- Access Economics Pty Limited. (2007, June). *Living with Parkinson's Disease: Challenges and Positive Steps for the Future*. Melbourne.
- Aiken, L.S. & West, S.G. (1991). *Testing and Interpreting Interactions*. Newbury Park, CA: Sage.
- Althaus, A., Arranz Becker, O., Spttke, A., Dengler, R., Schneider, F., Kloss, M., et al. (2008). Frequency and treatment of depressive symptoms in a Parkinson's disease registry. *Parkinsonism & Related Disorders, 14*, 626-632.
- Arrnulf, I., Konofal, E., Merino-Andreu, M., Houeto, J.L., Mesnage, V., Welter, M.L., et al. (2002). Parkinson's disease and sleepiness. *Neurology, 58*, 1019-1024.
- Australian Bureau of Statistics (ABS). *Australian Labor Market Statistics, July 2007*. Retrieved June 14, 2009, from <http://www.census.abs.gov.au/AUSSTATS/>.
- Australian Bureau of Statistics (ABS), (2009). *Australian Social trends*. Retrieved February 7 2010, from <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4102.0Main+Features20Sep+2009>.
- Baanders, A. N., P. M. Rijken, et al. (2002). Labour participation of the chronically ill - a profile sketch. *European Journal of Public Health, 12*, 124-130.

- Baatile, J., Langbein, W.E., Weaver, F., Maloney, C., & Jost, M.B. (2000). Effect of exercise on perceived quality of life of individuals with Parkinson's disease. *Journal of Rehabilitation Research and Development* 37, 529-534.
- Bambra, C., Whitehead, M., & Hamilton, V. (2005). Does 'welfare-to-work' work? A systematic review of the effectiveness of the UK's welfare-to-work programmes for people with a disability or chronic illness. *Social Science & Medicine*, 60, 1905-1918.
- Bandura, A. (1986). The explanatory and predictive scope of self-efficacy theory. *Journal of Social and Clinical Psychology*, 4, 359-373.
- Banks, P. & Lawrence, M. (2006). The Disability Discrimination Act, a necessary, but not sufficient safeguard for people with progressive conditions in the workplace? The experiences of younger people with Parkinson's disease. *Disability and Rehabilitation*, 28, 13-24.
- Behari, M., Srivastava, A.K., & Randey, R.M. (2005). Quality of life in patients with Parkinson's disease. *Parkinsonism & Related Disorders*, 11, 221-226.
- Blalock, A. C., McDaniel, J.S., & Farber, E.W. (2002). Effect of employment on quality of life and psychological functioning in patients with HIV/AIDS. *Psychosomatics*, 43, (5).
- Bradley, D. E. & Roberts, J.A. (2004). Self-employment and job satisfaction: investigating the role of self-efficacy, depression and seniority. *Journal of Small Business Management* 42, 37-58.
- Brod, M., Mendelsohn, G.A., & Roberts, B. (1998). Patients' experiences of Parkinson's disease. *Journal of Gerontology* 53, 213-222.
- Caap-Ahlgren, M. & Dehlin, O. (2001). Insomnia and depressive symptoms in patients with Parkinson's disease. Relationship to health-related quality of life. An interview study of patients living at home. *Archives of Gerontology and Geriatrics*, 32, 23-33.
- Calne, S. M. & Kumar, A. (2008). Young onset Parkinson's disease. Practical management of medical issues. *Parkinsonism & Related Disorders*, 14, 133-142.

- Calne, S. M., Lidstone, S.C. & Kumar, A. (2008). Psychosocial issues in young-onset Parkinson's disease: current research and challenges. *Parkinsonism & Related Disorders* 14, 143-150.
- Caplan, (1980) as cited in Fields, D.L. (2002). *Taking the Measure of Work; a Guide to Validated Scales for Organizational Research and Diagnosis*. Thousand Oaks, California: Sage.
- Carod-Artal, F. J., Ziomkowski, S., Hudson, M.M., & Martinez-Martin, P. (2008). Anxiety and depression: main determinants of health-related quality of life in Brazilian patients with Parkinson's disease. *Parkinsonism & Related Disorders*, 14, 102-108.
- Chibnall, J. T. & Tait, R.C. (1990). The Quality of Life Scale: a preliminary study with chronic pain patients. *Psychology and Health*, 4, 283-292.
- Corbin, J. M. & Strauss, A.L. (2008). *Basics of Qualitative Research*. Thousand Oaks, California, Sage.
- Cubo, E., Rojo, A., Ramos, S., Quintana, S., Gonzalez, M., Kompolti, K., et al. (2002). The importance of educational and psychological factors in Parkinson's disease quality of life. *European Journal of Neurology*, 9, 589-593.
- Cummings, J. L. & Masterman, D.L. (1999). Depression in patients with Parkinson's disease. *International Journal of Geriatric Psychiatry*, 14, 711-718.
- Dakof, G. A. & Mendelsohn, G.A. (1986). Parkinson's disease: the psychological aspects of a chronic illness. *Psychological Bulletin*, 99, 375-387.
- De Lange, A. H., Taxis, T.W., Kompier, M.A.J., Houtman, I.L.D., & Bongers, P.M. (2004). The relationships between work characteristics and mental health: examining normal, reversed and reciprocal relationships in a 4-wave study. *Work & Stress*, 18, 149-166.
- Den Ouden, B. L., Van Heck, G.L., & De Vries, J. (2007). Quality of life and related concepts in Parkinson's disease: a systematic review. *Movement Disorders*, 11, 1528-1537.

- Detaille, S., Haafkens, J.A., & van Dijk, F. (2003). What employees with rheumatoid arthritis, diabetes mellitus and hearing loss need to cope at work. *Scandinavian Journal of Work and Environmental Health*, 29, 134-142.
- Dodel, R., Peter, H., Spottke, A., Noelker, C., Althaus, A., Siebert, U., et al. (2007). Health-related quality of life in patients with narcolepsy. *Sleep Medicine*, 8, 733-741.
- Duvosin, R. (1984). *Parkinson's Disease: A Guide for Patient and Family*. Raven Press.
- Ellgring, H., Seiler, S., Perleth, B., Frings, W., Gasser, T., & Oertel, W. (1993). Psychosocial aspects of Parkinson's disease. *Neurology*, 43, Supp 6.
- Fields, D.L. (2002). *Taking the Measure of Work: a Guide to Validated Scales for Organizational Research and Diagnosis*. Thousand Oaks, California: Sage.
- Fleer, J., Hoekstra, H.J., Sleijfer, D.T., Tuinman, M.A., Klip, E.C., & Hoekstra-Weebers, J.E.H.M. (2006). Quality of life of testicular cancer survivors and the relationship with sociodemographics, cancer-related variables, and life events. *Support Care Cancer*, 14, 251-259.
- Frazier, L. D. (2000). Coping with disease-related stressors in Parkinson's disease. *The Gerontologist* 40, 53-64.
- Friedman, J. H., Brown, R.G., Comella, C., Garber, C.E., Krupp, L.B. & Lou, J.S. (2006). Fatigue in Parkinson's Disease: a review. *Movement Disorders*, 22, 297-308.
- Fujii, C., Aoshima, T., Sato, S., Mori, N., Ohkoshi, N., & Oda, S. (1997). Self-efficacy and related factors related to Parkinson's disease patients. *Nippon Koshu Eisei Zasshi*, 44, 817-826.
- Jukuoka, Y., Dracup, K.I., Takeshima, M., Ishii, N., Makaya, M., Groah, L., Kiriakidis, E. (2009). Effect of job strain and depressive symptoms upon returning to work after acute coronary syndrome. *Social Science & Medicine*, 68, 1897-1881.

- Gignac, M. A. M. (2005). Arthritis and employment: an examination of behavioral coping efforts to manage workplace activity limitations. *Arthritis & Rheumatism*, 53, 328-336.
- Gignac, M. A. M., Sutton, D., & Badley, E.M. (2007). Arthritis symptoms, the work environment, and the future: measuring perceived job strain among employed persons with arthritis. *Arthritis & Rheumatism-Arthritis Care and Research*, 57, 738-747.
- Graetz, B. (1993). Health consequences of employment and unemployment – longitudinal evidence for young men and women. *Social Science & Medicine*, 36, 715-724.
- Hasselhorn, H.M., Conway, P.M., Widerszal-Bazyl, M., Simon, M., Tackenberg, Pl, Schmidt, S., et al. (2008). Contribution of job strain to nurses' consideration of leaving the profession – results from the longitudinal European nurses' early exit study. *Scandinavian Journal of Work Environment & Health, Supp 6*, 75-82.
- Heider, D., Kitze, K., Zieger, M., Riedel-Heller, S.G., & Angermeyer, C. (2007). Health-related quality of life in patients after lumbar disc surgery: a longitudinal observational study. *Quality of life research*, 16, 453-1460.
- Henry, J. D. & Crawford, J.R. (2005). The short-form version of the Depression Anxiety Stress Scales (DASS-21): construct validity and normative data in a large non-clinical sample. *British Journal of Clinical Psychology*, 44, 227-239.
- Herlofson, K. & Larsen, J.P. (2003). The influence of fatigue on health-related quality of life in patients with Parkinson's disease. *Acta of Neurology of Scandanavia*, 107, 1-6.
- Hoehn, M. M. & Yahr, M.D. (1967). Parkinsonism: onset, progression, and mortality. *Neurology*, 17, 427-442.
- Hodgson, J.H., Garcia, K., & Tyndall, L. (2004). Parkinson's disease and the couple relationship: a qualitative study. *Family Systems & Health*, 22, 101-118.
- Jackson, C. J., Furnham, A., & Willen, K. (2000). Employer willingness to comply with the Disability

- Discrimination Act regarding staff selection in the UK. *Journal of Occupational and Organizational Psychology*, 73, 119-129.
- Jackson, P. R., Wall, T.D., Martin, R., & Davids, K. (1993). New measures of job control, cognitive demand and production responsibility. *Journal of Applied Psychology*, 78, 753-762.
- Jaysinghe, U. W., Proudfoot, J., Holton, C., Powell Davies, G., Amoroso, C., Bubner, T., et al. (2008). Chronically ill Australians' satisfaction with accessibility and patient-centredness. *International Journal for Quality in Health Care*, 20, 105-114.
- Jimmieson, N. L. (2000). Employee reactions to behavioural control under conditions of stress: the moderating role of self-efficacy. *Work & Stress*, 14, 262-280.
- Johnson, K. L., Klasner, E.R., Amtmann, D., Kuehn, C.M., & Yorkston, K.M. (2004). Medical, psychological, social, and programmatic barriers to employment for people with multiple sclerosis. *Journal of Rehabilitation*, 70, 38-49.
- Karasek, R. A. (1979). Job demands, job decision latitude and mental strain: implications for job redesign. *Administrative Science Quarterly*, 24, 285-307.
- Karasek, R.A., Baker, D., Marxer, F., Ahlbom, A., & Theorell, T. (1981). Job decision latitude, job demands and cardiovascular disease: a prospective study of Swedish men. *American Journal of Public Health*, 71, 694-705.
- Karasek, R. A., & Triantis, K.P. & Chaudhry, S.S. (1982). Coworker and supervisor support as moderators of associations between task characteristics and mental strain. *Journal of Occupational Behaviour* 3, 181-200.
- Karlsen, K.H., Larsen, J.P., Tandberg, E., & Jørgensen, K. (1999). Fatigue in patients with Parkinson's disease. *Movement Disorders*, 14, 237-241.
- Karlsen, K. H., Larsen, J.P., Tandbert, E., & Mæland, J.G. (1998). Quality of life measurements in patients with Parkinson's disease: a community-based study. *European Journal of Neurology*, 5, 443-450.

- Klepac, N., Trkulja, V., Relja, M., & Babić, T. (2008). Is quality of life in non-demented Parkinson's disease patients related to cognitive performance? A clinic-based cross sectional study. *European Journal of Neurology, 15*, 128-133.
- Koch, L. C., Egbert, N., Coeling, H., & Ayers, D. (2005). Returning to work after the onset of illness: experiences of right hemisphere stroke survivors. *Rehabilitation Counseling Bulletin, 48*, 209-218.
- Koch, L. C. & Rumrill, P. (2001). Illness and demographic correlates of quality of life among people with multiple sclerosis. *Rehabilitation Psychology, 46*, 145-164.
- Koplas, P. A., Gans, H.B., Wisely, M.P. & Kuchibhatia, M. (1999). Quality of life and Parkinson's disease. *The journals of Gerontology: Series A: Biological Sciences and Medical Sciences, 54*, 197-203.
- Korczyn, A. D. (2006). Management of sleep problems in Parkinson's disease. *Journal of Neurological Sciences, 248*, 163-166.
- Krupp, L.B., LaRocca, N.G., Muir-Nash, J., & Steinberg, A.D. (1989). The Fatigue Severity Scale; application to patients with multiple sclerosis and systemic lupus erythematosus. *Archives of Neurology, 46*, 1121-1123.
- Kuopio, A.-M., Reijo, J.M., Helenius, H., Toivonen, M. & Rinne, U.K. (2000). The quality of life in Parkinson's disease. *Movement Disorders, 15*, 216-223.
- Lamontagne, A.D., Keegal, T., Vallance, D., Ostry, A., Wolfe, R. (2008). Job strain – attributable depression in a sample of working Australians: assessing the contribution to health inequalities. *BMC Public Health, 8*, 181.
- Liamputtong, P. (2009). *Qualitative Research Methods*. Melbourne: Oxford University Press.
- Lee, M. A., Walker, R.W., Hildreth, A.J., & Prentice, W.M. (2006). Individualized assessment of quality of life in idiopathic Parkinson's disease. *Movement Disorders, 21*, 1929-1934.

- Lee, M. K., Lee, K.M., Bae, J.-M., Kim, S., Kim, Y.-W., Ryu, K.W., et al. (2008). Employment status and work-related difficulties in stomach cancer survivors compared with the general population. *British Journal of Cancer*, 98, 708-715.
- Lee, R. T. & Ashforth, B.E. (1993). A further examination of managerial burnout: toward an integrated model. *Journal of Organizational Behavior*, 14, 3-20.
- Lidal, I. B., Huynh, T.K., & Biering-Sørensen, F. (2007). Return to work following spinal cord injury. *Disability and Rehabilitation*, 29, 1341-1375.
- Liem, R. & Liem, J.H. (1988). Psychological effects of unemployment on workers and their families. *Journal of Social Issues*, 44, 87-105.
- Lillefjell, M., Krokstad, S., & Espnes, G.A. (2006). Factors predicting work ability following multidisciplinary rehabilitation for chronic musculoskeletal pain. *Journal of Occupational Rehabilitation*, 16, 543-555.
- Lim (1980) as cited in Fields, D.L. (2002). *Taking the Measure of Work: a Guide to Validated Scales for Organizational Research and Diagnosis*. Thousand Oaks, California: Sage.
- Lincoln, K. D. (2000). Social support, negative social interactions and psychological well-being. *Social Service Review*, June.
- Lovibond, P. F. & Lovibond, S.H. (1995). The structure of negative emotional states: comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behavioral Research Therapy*, 33, 335-343.
- Lyons, K.D., & Tickle-Degnen, L. (2003). Dramaturgical challenges of Parkinson's disease. *OTJR*, 23, 27-35.
- MacCarthy, & Brown, R. (1989). Psychosocial factors in Parkinson's disease. *British Journal of Clinical Psychology*, 28, 41-52.

- Manne, S. & Schnoll, R. (2001). Measuring supportive and unsupportive responses during cancer treatment: a factor analytic assessment of the partner responses to Cancer Inventory. *Journal of Behavioral Medicine*, 24, 297-321.
- Manoccia, M., Keller, S., & Ware, J.E. (2001). Sleep problems, health-related quality of life, work functioning and health care utilization among the chronically ill. *Quality of Life Research*, 10, 331-345.
- Marjama-Lyons, J. M. & Koller, W.C. (2001). Parkinson's disease: update in diagnosis and symptom management. *Geriatrics*, 56, 24-35.
- Martikainen, K. K., Luukkaala, T.H., & Reijo, J.M. (2006). Parkinson's disease and working capacity. *Movement Disorders*, 21, 2187-2191.
- Maunsell, E., Brisson, C., Dubois, L., Lauzier, S., & Fraser, A. (1999). Work problems after breast cancer: an exploratory qualitative study. *Psycho-oncology*, 8, 467-473.
- Mausner-Dorsch, H. & Eaton, W.W. (2000). Psychosocial work environment and depression: epidemiologic assessment of the demand-control model. *American Journal of Public Health*, 90, 1765-1770.
- McCabe, M.P., Firth, L., & O'Connor, E. (2009). Mood and quality of life among people with progressive neurological illnesses. *International Journal of Clinical Health and Psychology* 9, 21-25.
- McCabe, M.P., Roberts, C., & Firth (2008). Work and recreational changes among people with neurological illness and their caregivers. *Disability and Rehabilitation*, 30, 600-610.
- McQuillen, A. D., Licht, M.H., & Licht, B.G. (2003). Contributions of disease severity and perceptions of primary and secondary control to the prediction of psychosocial adjustment to Parkinson's disease. *Health psychology*, 22, 504-512.
- Melamed, S. & T. Kushnir (1991). Attenuating the impact of job demands: additive and interactive effects of perceived control and social support. *Journal of Vocational Behavior*, 39, 40-53.

- Merz, M. A., Bricout, K/C/ & Koch, L.C. (2001). Disability and job stress: implications for vocational rehabilitation planning. *Work*, 17, 85-95.
- Munir, F., Jones, D., Leka, S., & Griffiths, A. (2005). Work limitations and employer adjustments for employees with chronic illness. *International Journal of Rehabilitation*, 8, 219-228.
- Murphy, G. C. & Athanasou, J.A. (1999). The effect of unemployment on mental health. *Journal of Occupational and Organizational Psychology*, 72, 83-99.
- Nauta, M.M., Liu, C., & Li, C.P. (2010). A cross-national examination of self-efficacy as a moderator of autonomy/job strain relationships. *Applied Psychology – an International Review*, 5, 159-179.
- Neylan, T. C. (2002). Neurodegenerative disorders: James Parkinson's essay on the shaking palsy. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 14, 222.
- Nijhof, G. (1995). Parkinson's disease as a problem of shame in public appearance. *Sociology of Health & Illness*, 17, 193-205.
- Noblet, A. (2003). Building health promoting work settings: identifying the relationship between work characteristics and occupational stress in Australia. *Health Promotion International*, 18, 351-359.
- Noblet, A., Graffam, J. & McWilliams, J. (2008). Sources of well-being and commitment of staff in the Australian Disability Employment Services. *Health and Social Care in the Community*, 16, 137-146.
- Noblet, A. & Rodwell, J. (2009). Identifying the predictors of employee health and satisfaction in a NPM environment. *Public Management Review*, 11, 663-683.
- Noblet, A., Rodwell, J. & McWilliams, J. (2006). Organizational change in the public sector: augmenting the demand control model to predict employee outcomes under new public management. *Work & Stress*, 20, 335-352.

- Nomura, K., Nakao, M., Takeuchi, T., & Yano, E. (2009). Associations of insomnia with job strain, control, and support among male Japanese workers. *Sleep Medicine, 10*, 626-629.
- Norton, T. R., Manne, S.L., Rubin, S., Hernandez, E., Carlson, J., Bergman, C. et al. (2005). Ovarian cancer patients' psychological distress: the role of physical impairment, perceived unsupportive family and friend behaviors, perceived control and self-esteem. *Health Psychology, 24*, 143-152.
- Orbon, K. H., Schermer, T.R., van der Gulden, J.W., Chaveannes, N.H., Akkermans, R.P., van Schayck, O.P., et al. (2005). Employment status and quality of life in patients with chronic obstructive pulmonary disease. *International Archives of Occupational and Environmental Health, 78*, 467-474.
- Patel, S., Greasey, K., & Watson, P.J. (2007). Barriers to rehabilitation and return to work for unemployed chronic pain patients: a qualitative study. *European Journal of Pain, 11*, 831-840.
- Patti, F., Pozzilli, C., Montanari, E., Pappalardo, A., Piazza, L., Levi, A., et al. (2007). Effects of education level and employment status on HRQoL in early relapsing-remitting multiple sclerosis. *Multiple Sclerosis, 13*, 783-791.
- Pryce, J., Munir, F., & Haslam, C. (2007). Cancer survivorship and work: symptoms, supervisor response, co-worker disclosure and work adjustment. *Journal of Occupational Rehabilitation, 17*, 83-92.
- Quittenbaum, B. H. & Grahn, B. (2004). Quality of life and pain in Parkinson's disease: a controlled cross-sectional study. *Parkinsonism & Related Disorders, 10*, 129-136.
- Rao, S. M., Huber, S.J., & Bornstein, R.A. (1992). Emotional changes with multiple sclerosis and Parkinson's disease. *Journal of Consulting and Clinical Psychology, 60*, 369-378.
- Ray, C. (1992). Positive and negative social support in a chronic illness. *Psychological Reports, 71*, 977-978.

- Reuther, M., Spottke, E.A., Klotsche, J., Riedel, O., Peter, H., Berger, K., et al. (2007). Assessing health-related quality of life in patients with Parkinson's disease in a prospective longitudinal study. *Parkinsonism & Related Disorders*, 13, 108-114.
- Revenson, T. A., Schiaffino, K.M., Majerovitz, S.D., & Gibofsky, A. (1991). Social support as a double-edged sword: the relation of positive and problematic support to depression among rheumatoid arthritis patients. *Social Science & Medicine*, 33, 807-813.
- Riazi, A., Hobart, J.C., Lamping, D.L., Fitzpatrick, R., Freeman, J.A., Jenkinson, C., et al. (2003). Using the SF-36 measure to compare the health impact of multiple sclerosis and Parkinson's disease with normal population health profiles. *Journal of Neurology Neurosurgery and Psychiatry*, 74, 710-714.
- Robinson, J. E. (2000). Access to employment for people with disabilities: findings of a consumer-led project. *Disability and Rehabilitation*, 22, 246-253.
- Rodrigues de Paula, F., Fuscaldi Teixeira-Salmela, L., Rocha de Brito, P., Danielli Coelho de Morais Faria, C., & Cardoso, F. (2006). Impact of an exercise program on physical, emotional and social aspects of quality of life of individuals with Parkinson's disease. *Movement Disorders*, 21, 1073-1077.
- Roessler, R.T., Fitzgerald, S.M., Rumrill, P.D., & Koch, L.C. (2001). Determinants of employment status among people with multiple sclerosis. *Rehabilitation Counseling Bulletin*, 45, 31-19.
- Roessler, R. T., Neath, J., McMahon, B.T., & Rumrill, P.D. (2007). Workplace discrimination outcomes and their predictive factors for adults with multiple sclerosis. *Rehabilitation Counseling Bulletin*, 50, 139-152.
- Roessler, R. T. & Rumrill, P.D. (1994). Strategies of enhancing career maintenance self-efficacy of people with multiple-sclerosis. *Journal of Rehabilitation*, 60, 54-59.
- Roessler, R. T. & Rumrill, P.D. (2003). Multiple sclerosis and employment barriers: a systemic perspective on diagnosis and intervention. *Work*, 21, 17-23.

- Roessler, R. T., Rumrill, P.D., & Fitzgerald, S.M. (2004). Predictors of employment status for people with multiple sclerosis. *Rehabilitation Counseling Bulletin*, 47, 96-103.
- Roessler, R.T., Turner, R.C., Robertson, J.L., & Rumrill, P.D. (2005). Gender and perceived illness severity: differential indicators of employment concerns for adults with multiple sclerosis? *Rehabilitation Counseling Bulletin*, 48, 66-74.
- Rubenis, J. (2007). A rehabilitational approach to the management of Parkinson's disease. *Parkinsonism and Related Disorders*, 13, 495-497.
- Rubenstein, L. M., DeLeo, A., & Chrischilles, E.A. (2001). Economic and health-related quality of life considerations of new therapies in Parkinson's disease. *Pharmacoeconomics*, 19, 729-752.
- Rumrill, P., Roessler, R., & Fitzgerald, S.M. (2004). Vocational rehabilitation-related predictors of quality of life among people with multiple sclerosis. *Journal of Vocational Rehabilitation*, 20, 155-163.
- Rumrill, P., Roessler, R., & Koch, L.C. (1999). Surveying the employment concerns of people with multiple sclerosis: a participatory action research approach. *Journal of Vocational Rehabilitation*, 12, 75-82.
- Rumrill, P., Roessler, R., Vierstra, C., Hennessey, Mary, & Staples, L. (2004). Workplace barriers and job satisfaction among employed people with multiple sclerosis: an empirical rationale for early intervention. *Journal of Vocational Rehabilitation*, 20, 177-183.
- Rumrill, P. D. & Hennessey, M.L. (2001). *Multiple Sclerosis: a Guide for Rehabilitation and Health Care Professionals*. Illinois, Charles Thomas Publishers.
- Salanova, M., Grau, R.M., & Martinez, I.M. (2005). Job demands and coping behaviour: the moderating role of professional self-efficacy. *Psicothema*, 17, 390-395.
- Samii, A., Nutt, J.G., & Ransom, B.R. (2004). Parkinson's disease. *The Lancet*, 363, 1783-1793.

- Scaravilli, T., Gasparoli, E., Rinaldi, F., Polesell, G., & Bracco, F. (2003). Health-related quality of life and sleep disorders in Parkinson's disease. *Neurological Science, 24*, 209-210.
- Schaubroeck, J. & Merritt, D.E. (1997). Divergent effects of job control on coping with work stressors: the key role of self-efficacy. *Academy of Management Journal, 40*, 738-754.
- Schrag, A. (2006). Quality of life and depression in Parkinson's disease. *Journal of Neurological Sciences, 248*, 151-157.
- Schrag, A. & Banks, P. (2006). Time of loss of employment in Parkinson's disease. *Movement Disorders, 21*, 1839-1843.
- Schrag, A., Ben-Shlomo, Y., & Quinn, N. (2000). Cross sectional prevalence survey of idiopathic Parkinson's disease and parkinsonism in London. *British Medical Journal, 321*, 21-22.
- Schrag, A., Hovris, A., Morley, D., Quinn, N., & Jahanshahi, M. (2003). Young- versus older-onset Parkinson's disease; impact of disease and psychosocial consequences.. *Movement Disorders, 18*, 1250-1256.
- Schrag, A., Jahanshahi, M., & Quinn, N. (2000). How does Parkinson's disease affect quality of life? A comparison with quality of life in the general population. *Movement Disorders, 15*, 1112-1118.
- Schrag, A., Jahanshahi, M., & Quinn, N. (2001). What contributes to depression in Parkinson's disease? *Psychological Medicine, 31*, 65-73.
- Schreurs, B. & van Emmerik, H. (2010). Job insecurity and employee health: the buffering potential of job control and job self-efficacy. *Work & Stress, 24*, 56-72.
- Schreurs, K. M. G., De Ridder, D.T.D., & Bensing, J.M. (2000). A one year study of coping, social support and quality of life on Parkinson's disease. *Psychology & Health, 15*, 109-122.

- Schwarzer, R. & Jerusalem, M. (1995). Generalized Self-Efficacy scale. *Measures in Health Psychology: a User's Portfolio*. A. Weinman, S. Wright and M. Johnston. Windsor, UK, NFER-NELSON: 35-37.
- Schwengel, A., Niti, M.M., Tang, C. & Mg, T.P. (2009). Continued work employment and volunteerism and mental well-being of older adults: Singapore longitudinal ageing studies. *Age and Ageing*, 38, 531-537.
- Shimbo, T., Goto, M., Morimoto, T., Hira, K., Takemura, M., Matsui, K., et al. (2004). Association between patient education and health-related quality of life in patients with Parkinson's disease. *Quality of Life Research*, 13, 81-89.
- Shirom, A., Toker, S., Berliner, S., & Shapira, I., (2008). The job demand-control-support model and stress-related low grade inflammatory responses among healthy employees: a longitudinal study. *Work & Stress*, 22, 138-152.
- Shulman, L. M., Taback, R.L., Rabinstein, A.A., & Weiner, W.J. (2002). Non-recognition of depression and other non-motor symptoms in Parkinson's disease. *Parkinsonism & Related Disorders*, 8, 193-197.
- Slawek, J., Derejko, M., & Piotr, L. (2005). Factors affecting the quality of life of patients with idiopathic Parkinson's disease: a cross-sectional study in an outpatient clinic attendees. *Parkinsonism & Related Disorders*, 11, 465-468.
- Sparks, K. & Cooper, C.L. (1999). Occupational differences in the work-strain relationship: towards the use of situation-specific models. *Journal of Occupational and Organizational Psychology*, 72, 219-229.
- Springer & Verlag (2003). The diagnosis of Parkinson's disease. *Neurological Science*, 24, 157-164.
- Strazdins, L., D'Souza, R.M., Lim, L.L.Y., Broom, D.H., & Rodgers, B. (2004). Job strain, job insecurity and health: rethinking the relationship. *Journal of Occupational and Health Psychology*, 9, 296-305.

- Suzukamo, Y., Ohbu, S., Kondo, T., Kohmoto, J., & Fukuhara, S. (2006). Psychological adjustment has a greater effect on health-related quality of life than on severity of disease in Parkinson's disease. *Movement Disorders, 21*.
- Tabachnick, B.G., & Fidell, L.S. (1996). *Using Multivariate Statistics* (3rd ed.). New York: Harper Collins.
- Taris, T.W. & Schreurs, P.J.G. (2009). Explaining worker strain and learning: how important are emotional job demands? *Anxiety Stress & Coping, 22*, 245-262.
- Tsaousides, T., Warshowsky, A., Ashman, T.A., Cantor, J.B., Spielman, L. & Gordon, W.A. (2009). The relationship between employment-related self-efficacy and quality of life following traumatic brain injury. *Rehabilitation Psychology, 54*, 299-305.
- van der Doef, M. & Maes, S. (1999). The job demand-control (-support) model of psychological well-being: a review of 20 years of empirical research. *Work & Stress, 13*, 87-114.
- Vanroelen, C., Levecque, K., & Louckx, F. (2009). Psychosocial working conditions and self-reported health in representative sample of wage-earners; a test of the different hypotheses of the Demand-Control-Support Model. *International Archives of Occupational and Environmental Health, 82*, 329-342.
- Varekamp, I., Verbeek, J.H.A.M., & van Dijk. (2006). How can we help employees with chronic diseases to stay at work? A review of interventions aimed at job retention and based on an empowerment perspective. *International Archives of Occupational and Environmental Health, 80*, 87-97.
- Wall, T., Jackson, P., Mullarkey, S., & Parker, S. (1996). Job strain and cardiovascular disease. *Annual Review of Public Health, 15*, 153-166.
- Wallace (2005). Job stress, depression and work-to-family conflict – a test of the strain and buffer hypotheses. *Relations Industrielles-Industrial Relations, 60*, 510-539.

- Wang, J.L., Schmitz, N., Dewa, C., & Stansfield, S. (2009). Changes in perceived job strain and the risk of major depression: results from a population-based longitudinal study. *American Journal of Epidemiology*, *169*, 1085-1091.
- Warr, P., Butcher, V., Robertson, I., & Callinan, M. (2004). Older people's well-being as a function of employment, retirement, environmental characteristics and role preference. *British Journal of Psychology*, *95*, 297-324.
- Warr, P., Jackson, P., & Banks, M. (1988). Unemployment and mental health: some British studies. *Journal of Social Issues*, *44*, 47-68.
- World Health Organisation (WHO) (1995). The World Health Organization Quality of Life Assessment (WHOQOL): position paper from the World Health Organization. *Social Science & Medicine*, *41*, 1403-1409.
- Zesiewicz, T. A., Patel-Larson, A., Hauser, R.A., & Sullivan (2007). Social Security Disability Insurance (SSDI) in Parkinson's disease. *Disability and Rehabilitation*, *29*, 1934-1936.
- Zotti, A. M., Balastroni, G., Cerutti, P., Ferrario, S.R., Angelino, E., & Miglloretti, M. (2007). Application of the General Perceived Self-Efficacy Scale in cardio rehabilitation. *Monaldi Archives of Chest Disease*, *68*, 178-183.

APPENDIX A

Outline for Interview at Stage One

Parkinson's, Employment and Quality of Life **Qualitative interview questions**

Introductory Script

Thank you for taking part in this project.

I know that you have already read a little about it but I'd just like to clarify a few things before we start. This is the second research project that I have been involved in to do with Parkinson's disease. The first project I did was to do with support networks, family, friends, support groups When I was working on it I discovered that there was hardly any research around looking into work related issues and yet many people taking part in the project talked about the effect that Parkinson's had had on their work situation and how this had in turn affected their lives. . So that is what I'm doing this time round, it seems to be a neglected area.

This interview is part of the first stage of research. Before putting together a questionnaire to be completed by a large number of people, I wanted to make sure that the questionnaire focuses on the right things, the things that are going to be relevant to work issues for people with Parkinson's. So this interview is really part of putting together that questionnaire. Does that make sense? Do you have any questions?

We'll probably be talking for about an hour. If you want to take a break at any time just let me know. If there is anything you don't wish to answer, just say so, everything is voluntary. I'll be audio taping the session and giving you a pseudonym on all records in order to maintain confidentiality. Is there any name you'd like to choose for that purpose? The tapes and transcriptions will remain confidential and all reports of the information I collect will use the false names. All this information is outlined in this information sheet and it also has details of people to contact if you have any concerns after the interview. I need you to give your consent to participating, so if you could sign this form here? You may want to just read through this and, please, feel free to ask any questions you may have at this point.

Open Questions for those still in the workforce

- 1) Would you like to tell me what sort of work you do?
- 2) How has Parkinson's affected you at work?
- 3) What has made things harder at work since having Parkinson's?²
- 4) What has helped you to work with Parkinson's?

Specific areas of discussion (ONLY to be used if themes not raised from above):

Disclosure

- Do people at work know about your diagnosis?
- Who did you tell first?
- When did you tell them?
- How did they react?

Have people treated you differently since diagnosis?

Importance of work role

- How important to you was work prior to diagnosis?
- How important is it to you now?
-

Job demand

- How demanding is your job?
- In what ways is your job demanding?

Job control

- Are you able to decide how you do your job?
- Have you been able to change how you do your job to accommodate Parkinson's?

Support from employer)

- Do you have the same role now as you did at time of diagnosis?
- What do you do differently at work since diagnosis?
- Have things been changed to make things easier for you since diagnosis?
- What would help make things easier for you to work with Parkinson's?

Other Social support

- Have people at work been supportive since your diagnosis?
- How have people been supportive?
- Are there others that have helped you deal with work issues since having Parkinson's (family, friends, GP)?
-

APPENDIX B

Letter of Approval to Conduct Research from Swinburne University Human Research Ethics Committee

Subject: SUHREC - Ethics Project 0607/165 - Ethics Clearance
Date: Tuesday, 16 November 2010 11:43 AM
From: Keith Wilkins <KWilkins@groupwise.swin.edu.au>
To: "<Louise Cooper <lou@clevermedia.com.au>"
Conversation: SUHREC - Ethics Project 0607/165 - Ethics Clearance

>>> Aimii Treweek 30/05/2007 1:26 PM >>>

To: Dr Simon Knowles, Faculty of Life and Social Sciences.

SUHREC - Prof. 0607/165- Parkinsons, Employment and Quality of Life.
Researchers: Dr Simon Knowles, Ms Louise Cooper, FLSS
Duration: Approved to 31 December 2007.

I refer to the revisions to your ethical clearance application for the above project as submitted to the Chair of SHESC2 (H&B-B) or delegated member (29 May 2007) for expedited ethical review.

I am pleased to advise that approval has now been given for the project to proceed, subject to the Chief Investigator forwarding the Secretary of SHESC2 a copy of the letter of support provided by Parkinson's Australia, and in line with standard ethics clearance conditions here outlined:

- All human research activity undertaken under Swinburne auspices must conform to Swinburne and external regulatory standards, including the current National Statement on Ethical Conduct in Research Involving Humans and with respect to secure data use, retention and disposal.
- The named Swinburne Chief Investigator/Supervisor remains responsible for any personnel appointed to or associated with the project being made aware of ethics clearance conditions, including research and consent procedures or instruments approved. Any change in Chief investigator/Supervisor requires timely notification and SUHREC endorsement.
- The above project has been approved as submitted for ethical review by or on behalf of SUHREC. Amendments to approved procedures or instruments ordinarily require prior ethical appraisal / clearance. SUHREC must be notified immediately or as soon as possible thereafter of (a) any serious or unexpected adverse effects on participants and any redress measures; (b) proposed changes to protocol; and (c) unforeseen events which might effect continued ethical acceptability of the project.

- At a minimum, an annual report on the progress of the project is required as well as at the conclusion (or abandonment) of the project.

- A duly authorised external or internal audit of the project can be undertaken at any time.

Please contact me if you have any enquiries or concerns about on-going ethics clearance. The SUHREC project number should be cited in communication.

Best wishes for Louise Cooper's project.

Yours sincerely,

Aimii Treweek
Secretary, SHESC2

Aimii Treweek
Research Administration Coordinator
Faculty of Life & Social Sciences
Swinburne University of Technology
Mail H31, PO Box 218
Hawthorn, VIC 3122
AUSTRALIA
Telephone: (+61 3) 9214 5017
Facsimile: (+61 3) 9214 5908
Email: atreweek@swin.edu.au
Website: www.swin.edu.au



APPENDIX C

Information and Informed Consent for Stage One

PARKINSON'S, EMPLOYMENT AND QUALITY OF LIFE

A Research Project conducted by Louise Cooper and Dr Simon Knowles

Supported by Parkinson's Victoria

Informed Consent

What this project is about

This project is the first to be undertaken in Australia looking at work related issues that are faced by people with Parkinson's and what effect they may have on a person's quality of life. As someone with Parkinson's who is currently in employment or has recently left employment, your participation in this study would be of great value. It is hoped that the data gained from this study may contribute to providing information for workers with Parkinson's, their employers and colleagues.

Research overseas into Parkinson's and other chronic illnesses indicates that there are specific concerns relevant to people in the workplace following a diagnosis. It seems clear that an awareness of these issues and the manner in which they can be best addressed could significantly improve a person's job satisfaction and this in turn is likely to make living with Parkinson's easier.

Workplace conditions in Australia are subject to specific cultural and industrial relations influences and therefore specialist research needs to be conducted if it is to be relevant to people with Parkinson's living in this country. This research project is supported by Parkinson's Victoria who are assisting by identifying suitable participants such as yourself. It also fulfils part of the requirements of the principal researcher's (Louise Cooper) Professional Doctorate in Psychology (Counselling) at Swinburne University of Technology.

Your involvement in this interview

Your voluntary participation in this interview is voluntary. It should take about 1 hour and is intended to be as relaxed and easy as possible. It consists of a series of questions regarding you and your present or past experience at work since receiving a Parkinson's diagnosis. If you wish to take a break at any time during the interview please ask Louise.

Confidentiality

The conversation will be audio taped and subsequently transcribed. At all times the information you provide will be kept confidentially and false first names will be used in the transcription and any literature produced resulting from the research in order to preserve your anonymity. You will be sent a copy of the transcript for approval and comment before the data is analysed.

Concerns and Complaints

Since this is a project that has particular relevance to you and your participation is voluntary, it is anticipated that the experience will feel worthwhile. However, should you have any concerns following the conduct of the interview the following details may be of assistance:

If you have any questions about the project please contact: Dr Simon Knowles, Phone: 9214 8206, sknowles@swin.edu.au.

If completion of this questionnaire leads to feelings of distress or raises issues you would like to discuss with a counselor, please contact: Swinburne Psychology Centre, Ph. 9214 8653 or Lifeline : Ph. 13 11 14 (24-hour).

If you have any concerns or complaints about the conduct of this project you can contact: Research Ethics Officer, Office of Research and Graduate Studies (H68), Swinburne University of Technology, PO Box 218, Hawthorn Vic 3122, Tel (03) 214 5218 or reethics@swin.edu.au



PARKINSON'S, EMPLOYMENT AND QUALITY OF LIFE

A Research Project conducted by Louise Cooper and
Dr Simon Knowles

Supported by Parkinson's Victoria

INFORMED CONSENT

I consent to participate in the project named above, the particulars of which have been explained to me. I have been provided with a copy of the project consent information statement and this consent form and any questions I have asked have been answered to my satisfaction.

Please circle your response to the following:

- | | | |
|--|-----|----|
| • I consent to be interviewed by the researcher | Yes | No |
| • I agree to allow the interview to be recorded by electronic device | Yes | No |
| • I agree to make myself available for further information if required | Yes | No |

I acknowledge that:

- My participation is voluntary and that I am free to withdraw from the project at any time without explanation;
- The project is for the purpose of research and not for profit;
- My personal information and details of my Parkinson's diagnosis will be collected and retained for the purpose of carrying out this project
- My anonymity is preserved and I will not be identified in publications or otherwise without my express written consent.

By signing this document you agree to participate in this project.

Name of participant

.....

Signature Date

.....

Name of Principal Investigator.

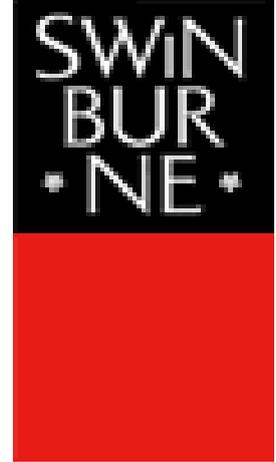
Signature Date

.....

(date)

APPENDIX D

Letter to Participants offering Opportunity to Review Interview Transcript (Stage One)



15th February 2008

Dear

Parkinson's, Employment and Quality of Life

Thank you once again for agreeing to participate in this project and my apologies for the delay in getting this transcript to you.

I have changed your name on the transcript to a randomly picked pseudonym for the purposes of confidentiality. If you have any objection to this particular name, please let me know. I have also omitted any identifying details eg names of family members.

I have enclosed two copies of the transcript and a stamped addressed envelope. This gives you the opportunity to use one copy to make deletions or any additional comments that you think may be of interest and return it to me. If there is nothing you wish to add please feel free to retain the two copies.

Following analysis of the data collected from interviews conducted last year, a survey on Parkinson's and Employment will be made available later this year for wider distribution.

Best wishes

Louise Cooper
lou@clevermedia.com.au
PO Box 180, Elwood, Vic 3184

APPENDIX E

Information and Questionnaire for Quantitative Study (Stage Two)

RESEARCH PROJECT

Researchers: Louise Cooper, Dr Simon Knowles & Prof Susan Moore

Parkinson's, Employment and Quality of Life

What this project is about

This project is the first to be undertaken in Australia looking at the work related issues that are faced by people with Parkinson's and what effect they may have on a person's quality of life. As someone with Parkinson's who is currently in employment, your participation in this study would be of great value. It is hoped that the data gained from this study may contribute to providing information for workers with Parkinson's, their employers and colleagues.

Research overseas into Parkinson's and other chronic illnesses indicates that there are specific concerns relevant to people in the workplace following a diagnosis. It seems clear that an awareness of these issues and the manner in which they can be best addressed could significantly improve a person's job satisfaction and this in turn is likely to make living with Parkinson's easier.

Workplace conditions in Australia are subject to specific cultural and industrial relations influences and therefore specialist research needs to be conducted if it is to be relevant to people with Parkinson's living in this country. This research project is supported by Parkinson's Victoria who is assisting in making the current survey available to participants. It also fulfils part of the requirements of the principal researcher's (Louise Cooper) Professional Doctorate in Psychology (Counselling) at Swinburne University of Technology.

What we would like you to do

The following survey contains questions relating to your experience of Parkinson's disease, your employment and issues that may be of concern to you at work since your diagnosis. The questionnaire should take you between 15 and 25 minutes to complete. Most questions require you to click or mark a circle in order to select one of a choice of responses and only a few require you to type or write briefly. The study requires you to complete the survey without assistance. If this is not possible,

assistance can be provided by phone from Louise Cooper (mob. 0408 051 290). A stamped envelope is provided for the return of paper copies. Submission of the questionnaire will be taken as your informed consent to participate.

Confidentiality:

All responses are strictly confidential and material received will only be viewed by the researchers at Swinburne University of Technology. Your response to this study is completely anonymous. The data may be presented at conferences, in journal publications or used for class exercises. Only group data will be presented and therefore no individual's responses will be identifiable.

Concerns:

If you have any questions about the project please contact:

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

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

Swinburne Psychology Clinic *OR* *Lifeline (24 hours)*
Ph. (03) 9214 8653 *ph. 131114*
(low cost counseling)

Complaints:

This project has been approved by or on behalf of Swinburne's Human Research Ethics Committee (SUHREC) in line with the National Statement on Ethical Conduct in Human Research. If you have any concerns or complaints about the conduct of this project, you can contact:

Research Ethics Officer, Swinburne Research (H68),
Swinburne University of Technology, P O Box 218, HAWTHORN VIC 3122.
Ph. (03) 9214 5218 or (03) 9214 5218 or resethics@swin.edu.au

Background information about you:

This information is required so that we can gain a general description of the people who participate in the survey. Please answer the questions by clicking on marking the appropriate circle.

1. What is your gender?

Male	<input type="radio"/>
Female	<input type="radio"/>

2. How old are you?

	years
--	-------

3. What is your marital status?

Single	<input type="radio"/>
Married (incl. de facto)	<input type="radio"/>
Divorced	<input type="radio"/>
Widowed	<input type="radio"/>

4. Where was your place of birth?

Australia	<input type="radio"/>
UK	<input type="radio"/>
New Zealand	<input type="radio"/>
Asia	<input type="radio"/>
Europe	<input type="radio"/>
Other	<input type="radio"/> :

Please specify _____

5. Is English your first language?

Yes	<input type="radio"/>	No	<input type="radio"/>
-----	-----------------------	----	-----------------------

6. What is the highest level of education you have achieved?

Primary	<input type="radio"/>
Some secondary	<input type="radio"/>
Secondary completed	<input type="radio"/>
Trade qualification	<input type="radio"/>
Tertiary Qualification	<input type="radio"/>
Postgraduate	<input type="radio"/>

7. How would you describe the area where you live?

Urban	<input type="radio"/>
Regional	<input type="radio"/>
Rural/Remote	<input type="radio"/>

Information about your Parkinson's:

8. How long have you been diagnosed with Parkinson's?

___ years ___ months

9. How long do you believe you have had Parkinson's symptoms?

_____ years _____ months

10.. Do you have other serious medical conditions?

Yes No

Please specify _____

11. Which of the following symptoms do you experience? (please mark as appropriate)

Slowness of movement

Stiffness

Posture problems

Tremor

Problems initiating movement

Muscle weakness

Speech problems

Problems with facial expression

The following questions are designed to measure the impact of fatigue on you.

During the past week I have found that:

		Disagree	←—————→						Agree
		1	2	3	4	5	6	7	
12.	My motivation is lower when I am fatigued	<input type="radio"/>							
13.	Exercise brings on my fatigue During the past week I have found that:	<input type="radio"/>							
		1	2	3	4	5	6	7	
14.	I am easily fatigued	<input type="radio"/>							
15.	Fatigue interferes with my physical functioning	<input type="radio"/>							
16.	Fatigue causes frequent problems for me	<input type="radio"/>							
17.	My fatigue prevents sustained physical functioning	<input type="radio"/>							
18.	Fatigue interferes with carrying out certain duties and responsibilities	<input type="radio"/>							
19.	Fatigue is among my three most disabling symptoms	<input type="radio"/>							
20.	Fatigue interferes with my work, family or social life	<input type="radio"/>							

About your Employment:

21. Are you currently working? Full-time Part-time
22. What is your occupation? _____
23. If you have changed occupation since diagnosis with Parkinson's, what was your occupation at time of diagnosis?

24. How big is the company you work for?
- Self-employed
- Less than 20 employees
- 20-199 employees
- 200+ employees
25. How would you best describe the work you do? (tick as many as appropriate)
- | | Not at all | Just a little | A moderate amount | Quite a lot | A great deal |
|----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Physically demanding | <input type="radio"/> |
| Mentally demanding | <input type="radio"/> |
| Socially demanding | <input type="radio"/> |
26. Does your job involve public speaking
- YES NO
27. How long have you been in your current employment? ___ years ___ months

		YES	NO	Not Applicable
28.	Have you changed jobs due to the effects of Parkinson's?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29.	Has your job changed in order to accommodate your Parkinson's?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30.	Have you reduced your hours because of your Parkinson's?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31.	Have you told your employer you have Parkinson's?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32.	Have you explained to your employer how Parkinson's affects you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33.	Have you told work colleagues you have Parkinson's?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34.	Have you explained to work colleagues how Parkinson's affects you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
35.	Have you told customer/clients you have Parkinson's?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
36.	Have you explained to customers/clients how Parkinson's affects you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

		Not at all	Just a little	A moderate amount	Quite a lot	A great deal
37.	At work do you decide on the order in which you do things?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
38.	Do you decide when to start a piece of work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
39.	Do you decide when to finish a piece of work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
40.	Do you set your own pace at work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
41.	Can you control how much work you do or produce?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
42.	Can you vary how you do your work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

43. Do you plan your own work?
44. Can you control the quality of what you do or produce?
45. Can you decide how to go about getting your job done?
46. Can you choose the methods to use in carrying out your work?

The following questions are designed to find out how much having Parkinson's interferes with your work. Please click on the appropriate circle to indicate how much you agree with the following statements on a scale from 1 to 5 where 1 = strongly agree and 5 = strongly disagree.

		1	2	3	4	5
		Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
47.	I'm often too tired at work because of Parkinson's	<input type="radio"/>				
48.	The consequences of Parkinson's are so great that they take away from my work	<input type="radio"/>				
49.	My superiors and peers dislike how often I am preoccupied with Parkinson's whilst at work	<input type="radio"/>				
50.	Parkinson's takes up time that I'd like to spend at work	<input type="radio"/>				

The following questions relate to how satisfied you are with your work. Indicate your response to the following statements by clicking on the appropriate circle on a scale of 1 to 5 where 1 = strongly agree and 5 = strongly disagree.

	1 Strongly agree	2 Agree	3 Undecided	4 Disagree	5 Strongly disagree
51. I am often bored with my job	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
52. I feel fairly well satisfied with my present job	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
53. I am satisfied with my job for the time being	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
54. Most days I am enthusiastic about my work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
55. I like my job better than the average worker does	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
56. I find real enjoyment in my work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The influence of other people:

The following questions concern the support that you believe you are getting from other people in relation to your work. Indicate your response by clicking on or marking the appropriate circle. How much does each of the following people go out of their way to do things to make your work life easier for you?

	Very much	Somewhat	A little	Not at all	Don't have such a person
57. Your immediate supervisor	<input type="radio"/>				
58. Other people at work	<input type="radio"/>				
59. Your wife/husband, partner, friends and relatives	<input type="radio"/>				

How easy is it to talk with each of the following people?

	Very much	Somewhat	A little	Not at all	Don't have such a person
60. Your immediate supervisor	<input type="radio"/>				
61. Other people at work	<input type="radio"/>				
62. Your wife/husband, partner, friends and relatives	<input type="radio"/>				

How much can each of these people be relied on when things get tough at work?

	Very much	Somewhat	A little	Not at all	Don't Have such a person
63. Your immediate supervisor	<input type="radio"/>				
64. Other people at work	<input type="radio"/>				
65. Your wife/husband, partner, friends and relatives	<input type="radio"/>				

How much is each of the following people willing to listen to your problems due to Parkinson's?

	Very much	Somewhat	A little	Not at all	Don't have such a person
66. Your immediate supervisor	<input type="radio"/>				
67. Other people at work	<input type="radio"/>				
68. Your wife/husband, partner, friends and relatives	<input type="radio"/>				

When people at work help you deal with your illness and its treatment, they may have many types of responses. The statements below are possible responses that they may have. Please rate each item as to HOW OFTEN people at work have responded in these ways DURING THE PAST 6-18 MONTHS.

		1-Never responded this way	2- Rarely responded this way	3-Some- times responded this way	4-Often responded this way
69.	Seemed impatient with you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
70.	Seemed angry or upset with you when doing things to help you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
71.	Seemed not to enjoy being around you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
72.	You had to wait a long time for help when you needed it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
73.	Avoided being around you when you were not feeling well	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
74.	Gave you the idea the that they did not really want to talk about the problem you were having	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
75.	Shouted or yelled at you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
76.	Did not seem to respect your feelings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
77.	Complained about your illness or about helping you with a task you found difficult to do by yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
78.	Seemed uncomfortable talking to you about your illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
79.	Criticised the way you handled your disease and or its treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
80.	Seemed less accepting of you since you got Parkinson's	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
81.	Was not emotionally supportive of you when you were expecting some support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Your Quality of Life

The following list of areas summarize the typical experiences that occur in daily living. We would like you to rate the extent to which your life is fulfilling (satisfying) in each of these realms. Rate the areas on a 1 to 7 scale for which 1 is totally unsatisfying, 4 is moderately satisfying and 7 is completely satisfying. Click on or mark the appropriate circle to respond.

	1	2	3	4	5	6	7
	Totally satisfy- ing			Moderately satisfying			Completely satisfying
82. Social-life and experiences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
83. Family-life and experiences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
84. Hobbies and recreational experiences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
85. Educational and intellectual development	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
86. The experience of daily living (e.g. work)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
87. Intimacy/sexual experiences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
88. Expectations and hopes for the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How you feel emotionally

The section is about you and your emotions over the *past week*. Do not spend too much time on each statement but click on or mark a circle in each line according to how much it applied to you.

	Did not apply to me at all	Applied to me to some degree or some of the time	Applied to me to a considerable degree or a good part of the time	Applied to me very much, or most of the time
89. I couldn't seem to experience any positive feeling at all	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
90. I felt that I had nothing to look forward to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
91. I felt I wasn't worth much as a person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
92. I felt down-hearted and blue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
93. I was unable to become enthusiastic about anything	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
94. I felt that life was meaningless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
95. I found it difficult to work up the initiative to do things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Your Self-efficacy – how you deal with life situations

This last section is made up of statements relating to how you generally deal with life situations. Click on or mark the appropriate circle according to how true the statement is for you.

		Not at all true	Hardly true	Moderately true	Exactly true
96.	I can always manage to solve difficult problems if I try hard enough	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
97.	If someone opposes me, I can find the means and ways to get what I want	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
98.	It is easy for me to stick to my aims and accomplish my goals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		Not at all true	Hardly true	Moderately true	Exactly true
99.	I am confident that I could deal efficiently with unexpected events	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
100.	Thanks to my resourcefulness, I know how to handle unforeseen situations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
101.	I can solve most problems if I invest the necessary effort	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
102.	I can remain calm when facing difficulties because I can rely on my coping abilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
103.	When I am confronted with a problem, I can usually find several solutions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
104.	If I am in trouble, I can usually think of a solution	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
105.	I can usually handle whatever come my way.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Thank you for your participation!

APPENDIX F

Letter of Approval to Conduct Research (Stage Two)
from Swinburne University Human Research Ethics Committee

Subject: SUHREC Project 0708/261 Ethics Clearance
Date: Tuesday, 16 November 2010 11:26 AM
From: Keith Wilkins <KWilkins@groupwise.swin.edu.au>
To: "<Louise Cooper <lou@clevermedia.com.au>"
Conversation: SUHREC Project 0708/261 Ethics Clearance

>>> Keith Wilkins 14/07/2008 4:45 PM >>>
To: Dr Simon Knowles/Ms Louise Cooper

Dear Simon and Louise

SUHREC Project 0708/261 Parkinson's, Employment and Quality of Life: The influence of control, social support and self-efficacy on working life for the chronically ill

Dr S Knowles FLSS Ms Louise Cooper Prof Susan Moore
Approved Duration: 11/07/2008 To 31/12/2009

I refer to the ethical review of the above project protocol undertaken by Swinburne's Human Research Ethics Committee (SUHREC). Your responses, as emailed on 9 July 2008 with attachment, were put to a delegate of SUHREC for consideration.

I am pleased to advise that the project (as submitted to date) has been cleared to proceed in line with standard on-going ethics clearance conditions here outlined.

- All human research activity undertaken under Swinburne auspices must conform to Swinburne and external regulatory standards, including the National Statement on Ethical Conduct in Human Research and with respect to secure data use, retention and disposal.

- The named Swinburne Chief Investigator/Supervisor remains responsible for any personnel appointed to or associated with the project being made aware of ethics clearance conditions, including research and consent procedures or instruments approved. Any change in chief investigator/supervisor requires timely notification and SUHREC endorsement.

- The above project has been approved as submitted for ethical review by or on behalf of SUHREC. Amendments to approved procedures or instruments ordinarily require prior ethical appraisal/ clearance. SUHREC must be notified immediately or as soon as possible thereafter of (a) any serious or unexpected adverse effects on participants and any redress measures; (b) proposed changes in protocols; and (c) unforeseen events which might affect continued ethical acceptability of the project.

- At a minimum, an annual report on the progress of the project is required as well as at the conclusion (or abandonment) of the project.

- A duly authorised external or internal audit of the project may be undertaken at any time.

Please contact me if you have any queries about on-going ethics clearance. The SUHREC project number should be quoted in communication.

Best wishes for the project.

Yours sincerely

Keith Wilkins
Secretary, SUHREC

Keith Wilkins
Research Ethics Officer
Swinburne Research (H68)
Swinburne University of Technology
P O Box 218
HAWTHORN VIC 3122
Tel +61 3 9214 5218
Fax +61 3 9214 5267



APPENDIX G

Flyer for Recruiting Respondents to Stage Two

RESEARCH PROJECT

Researchers: Louise Cooper, Dr Simon Knowles &

Prof Susan Moore

Parkinson's, Employment and Quality of Life

Seeking Participants

We are looking for people to take part in a research project looking at the experience of people with Parkinson's in the work place. If you are currently in full or part-time employment and have Parkinson's disease, you may be interested in participating. If you know of someone with Parkinson's who is currently working, perhaps you could pass on this information.

Participation is, of course, voluntary and anonymous and would involve the completion of a questionnaire that will take between 15 and 25 minutes. Questions relate to your experience of Parkinson's disease, your employment, and issues that may be of concern to you at work since diagnosis.

This project is the first to be undertaken in Australia looking at work related issues that are faced by people with Parkinson's and what effect they may have on a person's quality of life. It is hoped that the data gained from this study may contribute to providing information for workers with Parkinson's, their employers and colleagues.

The questionnaire can be completed at:

<http://opinio.online.swin.edu.au/s?s=4356>

or contact Louise Cooper on 0408 051 290 or lcooper@swin.edu.au for a copy to be sent to you.

APPENDIX H

Wording for Facebook Advertisement (Stage Two Recruitment)

Parkinson's Research

If you have Parkinson's Disease and work full- or part-time, tell us about your employment experience in an online survey.

Click here for link to survey