Keeping Working to Keep Working: Staying in the Workforce with a Diagnosis of Parkinson’s Disease

Elissa Brittenden

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Declaration:

Name of candidate: Elissa Brittenden

This thesis entitled Keeping working to keep working: Staying in the workforce with a diagnosis of Parkinson’s disease is submitted in partial fulfilment for the requirements for the Unitec degree of Master of Osteopathy.

Candidate’s declaration

I confirm that:

- This thesis represents my own work.
- Research for this work has been conducted in accordance with the Unitec Research Ethics Committee Policy and Procedures, and has fulfilled any requirements set for this project by the Unitec Research Ethics Committee.
- Ethics Approved by the Unitec Research Ethics Committee Policy and Procedures (2015-1055)

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Abstract

Background: Parkinson’s disease has a profound effect on those with the condition. Due to earlier diagnosis from improved diagnostic techniques as well as advances in medication, people are often able to continue to work for many years after diagnosis. This study sought to discuss the experience of a small group of people in New Zealand with Parkinson’s disease who continue to work after diagnosis.

Aim: To explore the experience of staying in the workforce after a diagnosis of Parkinson’s disease.

Design: A qualitative study using interpretive description.

Methods: Five participants were recruited through purposive sampling via word of mouth and an advertisement placed in the Parkinson’s New Zealand newsletter. Data were collected by semi-structured interviews and analysed thematically.

Findings: Three themes were identified: ‘participating in work’, ‘trying to reinvent’ and ‘bridging past and future’. Each interwove into an overarching theme of ‘working to work’ in that participants still wished to participate in work but in order to do this had to make adaptions and use strategies to ensure work could continue. They faced an uncertain future and spoke of their past while looking forward with hesitation.

Conclusion: The data revealed that working remained an important part of participants’ lives after a diagnosis of Parkinson’s disease. In order to keep working they made adaptions to their lives so this could continue in a way they wanted.

Keywords: Parkinson’s disease, lived experience, interpretive description, work, occupation, New Zealand.
Preface

This research study explored the experience of staying in the workforce after a diagnosis of Parkinson’s disease in New Zealand. Participants who were part of the study were interviewed by the researcher. Their responses were analysed in order to add to the body of knowledge of the phenomenon.

The thesis is presented in three parts. Part one is in three chapters. Chapter one is an introduction to the research, chapter two is a literature review to introduce the reader to relevant literature on the subject and chapter three provides a description of the methodology and method employed in the study. Part two of the thesis is presented as a manuscript. It contains the results and discussion in manuscript style with formatting and referencing to suit publication, as stipulated by the Scandinavian Journal of Caring Sciences (Appendix 1).

Part three of the thesis includes the appendices; these document the participant information sheet, consent form, interview schedule and ethical approval in the study. There is also an example of the processes undertaken in data analysis.
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Firstly, to my wonderful supervisors Elizabeth Niven and Dianne Roy, thank you for your support, encouragement and guidance through this unfamiliar process. Your insights and knowledge with all the aspects that made up this research project have made it a much smoother process than I thought it was going to be.

A special thank you to my five participants, I am so grateful to you for your time and for sharing your personal experiences with me. I hope this study speaks to you all in some way and tells some of your story.

To my family and friends, I am indebted to you for your encouragement and support. I so look forward to seeing you all.

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## Glossary

<table>
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<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td><strong>Bradykinesia</strong></td>
<td>One of the four cardinal motor features of Parkinson’s disease. A slowing down and loss of spontaneous and voluntary movements. From the Greek words <em>brady</em> = slow and <em>kinesia</em> = movement</td>
</tr>
<tr>
<td><strong>Fatigue</strong></td>
<td>A state of tiredness or exhaustion that cannot be remedied by rest. Decreases capacity for normal activity (Zwarts, Bleijenberg, &amp; van Engelen, 2008)</td>
</tr>
<tr>
<td><strong>Gait disturbance</strong></td>
<td>See postural instability</td>
</tr>
<tr>
<td><strong>Levodopa</strong></td>
<td>Most commonly used medication for the treatment of Parkinson’s disease. Crosses the blood-brain barrier to replace dopamine</td>
</tr>
<tr>
<td><strong>Long-term condition</strong></td>
<td>Defined here using the New Zealand Ministry of Health definition: “Any ongoing, long-term or recurring conditions that can have a significant impact on people’s lives” (National Health Committee, 2007, p. 7). May also be referred to as chronic condition/chronic disease</td>
</tr>
<tr>
<td><strong>Occupation</strong></td>
<td>Described as tasks and activities that relate to leisure, productivity as well as self-care (Ottenvall Hammar &amp; Håkansson, 2012)</td>
</tr>
<tr>
<td><strong>Parkinson’s disease</strong></td>
<td>Progressive, degenerative neurological condition characterised by bradykinesia, postural instability, resting tremor and rigidity</td>
</tr>
<tr>
<td><strong>Postural instability</strong></td>
<td>One of the four cardinal motor features of Parkinson’s disease. Difficulty with walking, standing, balance and coordination</td>
</tr>
<tr>
<td><strong>Quality of life (QoL)</strong></td>
<td>The subjective and objective measurement of a range of life domains and individual values. Includes: physical, emotional, material and social wellbeing (Felce &amp; Perry, 1995)</td>
</tr>
<tr>
<td><strong>Resting tremor</strong></td>
<td>One of the four cardinal motor features of Parkinson’s disease. Involuntary, uncontrollable movements in a limb while at rest. Ceases for the duration of voluntary movement</td>
</tr>
<tr>
<td><strong>Rigidity</strong></td>
<td>One of the four cardinal motor features of Parkinson’s disease. Abnormal stiffness in a limb or another body part</td>
</tr>
<tr>
<td><strong>Sinemet™</strong></td>
<td>Brand name of the most commonly prescribed levodopa medication</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>------</td>
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</tr>
<tr>
<td>Tremor</td>
<td>Movement that is involuntary, rhythmic (slow or fast) and uncontrollable. Can occur in hands, feet, limbs or head</td>
</tr>
<tr>
<td>Work</td>
<td>Defined here as “employment in a formal, paid position” (Hinterlong, Morrow-Howell, &amp; Rozario, 2007, p. 354)</td>
</tr>
</tbody>
</table>
Part One Chapter One:

Introducing the Research
Part One Chapter One: Introduction

Introduction
The aim of this thesis was to explore the experience of staying in the workforce after a diagnosis of Parkinson’s disease (PD). It provides an interpretive description of the experiences of five New Zealanders with PD who continue to work. The introduction gives the background to the topic, including a section on PD in New Zealand and the resources available to those who have it. The research topic is introduced and the processes of undertaking the research outlined. The introduction continues with a summary of the literature that contributes to the question asked in the study, it concludes with an outline of the methodology and methods used in the research.

Research question
What is the experience of continuing to work after a diagnosis of PD?

Methodological approach to the study
This thesis is a qualitative study that utilised interpretive description, developed by Thorne, Reimer Kirkham and MacDonald-Emes (1997) and described by Thorne (2008), as methodology.

Background to Parkinson’s disease
PD is a long-term neurological condition highly prevalent both worldwide and within New Zealand. It is the second most common neurological condition, after Alzheimer’s disease (Wirdefeldt, Adami, Cole, Trichopoulos, & Mandel, 2011), affecting approximately seven to ten million people throughout the world (Parkinson’s Disease Foundation Inc., 2014). Parkinson’s New Zealand state that the number in New Zealand is approximately 10,000 (“Parkinson’s New Zealand,” n.d.). While PD is rare in those under the age of 50 years, its prevalence increases with age (de Lau & Breteler, 2006). Recent estimates put the number of those with PD in the worldwide population over the age of 60 years at 1% (de Lau & Breteler, 2006). It is widely, though not universally, agreed that more men are diagnosed with PD when compared to women. Most authors believe that the numbers are 1.5 men to 1 woman (van Den Eeden et al., 2003). There is little understood about why this is the case but it is considered that oestrogen may provide a neuroprotective role (Wirdefeldt et al., 2011). To date no data were found that state the gender ratio of PD in New Zealand.
Although the exact cause of PD is unclear, it is usually idiopathic (Obeso et al., 2010). There does appear to be a genetic connection of up to 10% for those who have a family history of PD (de Lau & Breteler, 2006). Environmental factors are considered a likely cause for a high percentage of PD and these include exposure to herbicides and industrial chemicals (Wirdefeldt et al., 2011). There is also emerging research to suggest a connection between the enteric nervous system and the progression of PD (Visanji, Brooks, Hazrati, & Lang, 2013). This connection will be discussed in more detail in the Braak theory of PD progression section of this introduction.

The clinical picture of PD is highly individualised but presents in three different forms: Akinetic/Rigid PD, Tremor-Dominant PD and a mixed type. The classic clinical features of PD are resting tremor, bradykinesia, rigidity and postural instability (Jankovic, 2008). The dominance of each of these symptoms will depend on the type of PD the person has.

Current understanding of the symptoms of PD is that it occurs because of the death of the dopamine producing cells in the substantia nigra compacta, as well as to the acetylcholine-producing cells within the pedunculopontine nucleus. The loss of dopamine released to the putamen reduces activity in the motor areas of the cerebral cortex and as a consequence voluntary movements in the body are reduced. This, in combination with the increased inhibition of the pedunculopontine nucleus, disinhibits the reticulospinal tracts and leads to excessive contraction of muscles as well as the other symptoms that typify PD (Lundy-Ekman, 2013)

There is currently no cure for PD; instead it is managed with a combination of pharmaceutical and surgical approaches. Levodopa, along with carbidopa, remain the best practice approaches, both internationally and within New Zealand, for symptom relief (Mestre & Ferreira, 2010). Carbidopa acts to inhibit the decarboxylation of levodopa within systemic circulation which leads to increased uptake of levodopa within the central nervous system (Rao, Hofmann, & Shakil, 2006). Levodopa crosses the blood-brain barrier and enters the brain where it is converted into dopamine; it then acts to replace the dopamine that is lost from the substantia nigra compacta. Relief occurs only short-term, however, and over time the effect of levodopa declines (Hayes, Fung, Kimber, & O’Sullivan, 2010).

People with PD may also be prescribed a wide variety of other medications to manage non-motor symptoms. For some patients these symptoms are just as bothersome as the motor
symptoms and include depression, dementia, hallucinations, rapid eye movement sleep
behaviour disorder, orthostatic hypotension and constipation (Jankovic, 2008).

**Diagnosis of Parkinson’s disease**

Part of the difficulty in finding accurate epidemiological data for the diagnosis of PD is that it
requires a diagnostic test that is both reliable and easily applicable, for which PD has neither
(de Lau & Breteler, 2006; Stern, Lang, & Poewe, 2012). Instead PD is diagnosed with a set of
clinical features and a patient must have at least two of these for a diagnosis of PD (Stern et
al., 2012). These features are: resting tremor, bradykinesia, rigidity or postural imbalance.
The diagnosis of PD is further supported by asymmetric onset of symptoms and that
symptoms respond well to treatment with levodopa (de Lau & Breteler, 2006; Stern et al.,
2012). Finally, Parkinsonism symptoms need to be ruled out as occurring due to a different
primary condition such as Alzheimer’s disease, stroke or Huntington’s disease (Wirdefeldt et
al., 2011).

**Braak theory of Parkinson’s disease progression**

Although PD has a set of classic symptoms, as described above, these usually appear long
after the condition has started having an effect of the body. There is research to indicate that
other, early symptoms begin before the motor symptoms (Braak, Ghebremedhin, Rüb,
Bratzke, & Del Tredici, 2004). These will still have an effect on the person’s quality of life
(QoL) but will typically be self-managed and may not be attributed to PD. The symptoms
will continue to be a part of a person’s clinical picture as other symptoms emerge.

The Braak theory of Parkinson’s disease progression was first presented in 2004 (Braak et
al.). It suggests that pathology enters the body through the enteric nervous system, within the
digestive system, where it then travels through the body to the medulla and olfactory bulb via
the vagus nerve. The theory is being researched in, amongst others, the neurology
departments of Lund University, Sweden (Holmqvist et al., 2014) as well as Helsinki
University, Finland (Schepersjans et al., 2015). It offers an explanation as to why there is often
a combination of symptoms experienced by a person and it has been shown that these
symptoms can begin several years prior to motor changes (Braak et al., 2003; Visanji et al.,
2013). Early symptoms include constipation and other autonomic symptoms, hyposmia, sleep
disturbance, depression, fatigue and low back pain (Visanji et al., 2013).
Support for people with Parkinson’s disease in New Zealand

Support for those who have PD includes services through the organisation Parkinson’s New Zealand. The organisation has 20 divisions across New Zealand. These provide information, education and care through home visits, support groups and quarterly newsletters. Support groups meet monthly, at various locations throughout New Zealand, including ten groups in Auckland. There are also support groups for carers of people with PD.

Other resources include biographies and autobiographies written by people with PD, both from within New Zealand as well as outside the country. Included in this is Ann Andrews book *Positively Parkinson’s* (2013) which contains chapters on symptom management, medication, treatment options and suggestions on self-care. Michael J. Fox, (2003, 2009, 2010), a well-known actor, has also written several books that describe his journey towards diagnosis and subsequent treatment of PD. There is a focus in his books on the experience of living with PD which had rarely been seen in autobiographies prior to this which may have given a voice to many people with the disease.

Further support is available through online blogs and message forums which exist in relation to PD. These forums can be monitored by doctors who give advice to people with PD (blog.patientslikeme.com/category/life-changing-conditions/pd/,) or offer a place where questions may be asked and support given on the day-to-day experience of living with PD (forum.parkinson.org/). Others are blogs are written by people who have PD (katekelsall.typepad.com/my_weblog/).

Summary
The introduction section gave a general overview of PD, including epidemiology, diagnosis and disease progression. Focus was then given to PD in New Zealand, including support for people with a diagnosis of the condition. In the following section a review of literature relating to the topic will be undertaken.
Part One Chapter Two: Literature Review

Background

In interpretive description the literature review is one of two elements that scaffold a study (Thorne, 2008). As Thorne describes, the literature review enables researchers to locate themselves “substantively, theoretically, and within a disciplinary orientation” (Thorne, 2008, p. 55). They discuss current knowledge on a subject and critically reflect on the strengths and weaknesses within the body of knowledge on a subject. The literature review below aims to include these elements so it supports the methodology of the research, interpretive description (Thorne, 2008).

The review of literature undertaken and reported here focusses first on the experience of people with long-term conditions. Emphasis is given to the importance of meaningful work, depression and fatigue. Attention is on how these relate to people with other long-term conditions as well as PD specifically. The review then addresses the experience of living with specific symptoms and side-effects of PD. These include freezing and gait changes, challenges to communication as well as sleep disturbances, autonomic changes, shame, the experience of deep brain stimulation and, finally, living with late-stage PD. To conclude the literature review osteopathic knowledge of PD is reviewed and examples of research into treatment undertaken by osteopaths of patients with PD discussed.

Literature review search strategy

Literature relating to the study of PD was identified through database searches including PubMed, Google Scholar, EBSCO, Science Direct and Research Gate. Keywords were: Parkinson’s disease; lived experience; work (working); occupation (occupations); chronic conditions; long-term conditions; chronic disease; osteopathy and Parkinson’s disease; osteopathy and long-term conditions; living with Parkinson’s disease and fatigue. Further literature was found using the reference lists of journal articles. During the research process autobiographies were also read, namely Ann Andrew’s Positively Parkinson’s (2013) and Michael J. Fox’s. Emphasis was given to current research, with data limitations set to articles written after the year 2000 where possible.

The study of long-term conditions

There is a variety of different definitions and terminology used when describing the term long-term conditions. In the past they have been referred to as chronic conditions or chronic diseases but, whilst these definitions may still stand, it is now more common to use the term
long-term condition. The change in terminology reflects a move away from words such as chronic or disease towards words that include less pathologising and labelling, or that have underlying meanings such as abnormal, crippling or different from the majority (Johnson & Chang, 2014).

In 2004 the World Health Organisation defined chronic conditions/diseases as having at least one of the following: they are permanent, create disability that is irreversible, cause pathological changes to anatomy and may require special training for the patient to manage or may require long-term care (World Health Organization, 2004). This description still fits with how long-term conditions are viewed. In 2007 the New Zealand National Health Committee defined long-term conditions as “any ongoing, long-term or recurring condition that can have a significant impact on people’s lives” (National Health Committee, 2007, p. 7). These conditions may not be immediately life-threatening but are a leading cause of premature death and they often “compromise quality of life through physical limitation and disability” (“Long Term Conditions,” n.d.). PD falls into the category of a chronic condition/disease because it meets all these criteria. The use of terminology in the current study will, however, reflect the current practice and use the term long-term condition rather than chronic condition/disease.

The incidence of long-term conditions is rising (Barnett et al., 2012; Remington & Brownson, 2011; World Health Organization, 2014) and is the primary challenge that healthcare services face (Barnett et al., 2012; World Health Organization, 2014). The reasons for the rise are complex but include the general ageing of the world’s population as well as improvements in diagnostic and management techniques (Remington & Brownson, 2011). Based on a population health survey seven out of every ten adults in New Zealand aged over 65 years have at least one long-term condition (Ministry of Health, 2015).

Qualitative research into the experiences of people who have long-term conditions has been somewhat overlooked by the dominance of quantitative research (Vishnevsky & Beanlands, 2004). There is a long history of qualitative research in nursing and sociology (Thorne & Paterson, 2000) but in contrast the traditional biomedical fields have focused on producing results that were “measurable, standardised and replicable” (Vishnevsky & Beanlands, 2004, p. 234). More recently, however, researchers in the biomedical field have wanted to gain a better understanding of the human experience in relation to illness – both acute and long-term – and there are many examples of qualitative research that address both of these (Broussard, 2006; Vishnevsky & Beanlands, 2004).
An interest in the perspective of people with long-term conditions is further reflected in research that examined how they wanted their healthcare to be delivered. In England Ziebland et al. (2014) utilised an archive of 3,500 qualitative, narrative interviews covering 60 different health issues. Although it did not include interviews with people with PD, another neurological condition, dementia, was represented in the data. Within the archive the authors found eight aspects of healthcare valued by people. These were then tested in focus groups of people from a range of different social and economic backgrounds, the focus being on people the researchers believe are under-represented in healthcare research such as old and young people. The aspects of healthcare that were valued by participants included being involved in decision-making, being able to engage in difficult decisions and sharing information across multiple health services. Of relevance for the current study is that participants also discussed the importance to them that a practitioner had an understanding of how their lives had been affected by an illness (Ziebland et al., 2014).

Furthermore, it is argued that evidence-based practice should not only include the use of best research evidence, but also take into consideration a patient’s own values, knowledge and experiences (Holmes, Lutz, Ravenek, & Rudman, 2013). According to Guyatt, Cook and Haynes (2004) gaining an understanding of these values, as well as of the knowledge and experience a person has into their illness, enables patients and practitioners to arrive at optimal decisions. Sunvisson (2006), a prominent researcher into the experience of living with PD, states that “to provide quality support and care for Parkinson’s disease patients [sic], we need medical knowledge about the disease and knowledge about the individual’s experiences throughout the progression of the disease” (p. 91).

Qualitative research examining the experience of people with long-term conditions is varied in scope and focus. Research includes an emphasis on how such people make decisions about their self-care, ageing while having a long-term condition and the importance of work. As well as these topics authors have also examined the level of occurrence and impact depression and fatigue has on people with long-term conditions. The following section gives an overview of the research on these topics as they relate to the current study.

**Making decisions about self-care**

Thorne, Paterson and Russell’s (2003) study acknowledged that most of the responsibility for self-care of people with long-term conditions lies with those affected. In this context, self-care management refers to the way people make decisions every day in regards to their nutrition, exercise, rest, medication as well as when and from whom to get help if symptoms
become difficult to cope with (Thorne et al., 2003). The authors argue that decisions people made every day impacted on their level of self-care. In their study, 22 participants with type 1 diabetes and 7 each with type 2 diabetes, HIV/AIDS and multiple sclerosis were interviewed. These conditions were chosen as, the authors argue, they represented conditions with enough variation between them so as to be able to identify differences as well as similarities. The authors found that participants valued making their own decisions, as it reflected the level of expertise they felt about their illness. Participants relayed a sense of being able to turn difficulties into strengths; of accepting imperfection and ambiguity as well as the importance of meaningful work (Thorne et al., 2003).

**Ageing with a long-term condition**

The research of Giddings, Roy and Predeger (2007) and Roy and Giddings (2012) used interpretive description to explore the experiences of women living with long-term conditions while ageing. Participants were aged between 50 and 58 years (Giddings et al., 2007) and 65 and 74 years (Roy & Giddings, 2012). Both studies were small, interviewing seven (Giddings et al., 2007) and nine women (Roy & Giddings, 2012) but utilised focus groups to use interaction as a way to bring memories and discussion from participants (Giddings et al., 2007; Roy & Giddings, 2012). The themes that emerged in these studies included that, for some, the process of ageing overshadowed the long-term condition (Roy & Giddings, 2012) and that the long-term condition became just a part of their lives (Giddings et al., 2007). Hewitt-Taylor, Bond, Hear and Barker (2013) also researched the experience of older people with a long-term condition. The authors found that, for their seven participants, it was difficult to distinguish between ageing and the worsening symptoms of their pre-existing long-term condition (Hewitt-Taylor et al., 2013). All the authors agree, however, that because of their long-term condition participants were able to interact with healthcare professionals, when faced with other health conditions, in a more confident manner (Hewitt-Taylor et al., 2013; Roy & Giddings, 2012). They had refined the skills and strategies needed to manage their condition and wished healthcare professionals would work in partnership with them because of their expertise (Hewitt-Taylor et al., 2013).

**Importance of meaningful work**

The importance of work for people with a long-term condition has been a factor established in research. Before discussing the findings, defining work is important as the definition can vary from study to study. Some describe it as an “activity with context and personal meaning” (Pierce, 2001, p. 139), but this definition could include a range of activities such as
gardening or caring for grandchildren. Other definitions say work is “contributing to the social and economic fabric of communities (productivity)” (Hammell, 2004, p. 297). Again, this could include a wide range of activities including volunteering or childcare without pay. It is important to also differentiate between occupation and work as again these have different meanings. Occupation has been referred to as the tasks or activities undertaken by people including their leisure, production and self-care (Ottenvall Hammar & Håkansson, 2012). This definition of occupation includes activity and tasks that go beyond that needed for the study undertaken here, with its focus on paid and formal employment. Indeed, for the study undertaken here work is defined as “employment in a formal, paid position” (Hinterlong et al., 2007, p. 354).

There has been a strong connection made between work and a person’s QoL. This connection was emphasised in research undertaken by Thorne et al. (2003), Caldas and Bertero (2007) and Hovbrandt, Fridlund and Carlsson (2007). These authors found that not only did ageing participants enjoy activities they considered useful, as it helped them feel engaged in life, but also that working added a sense of continuity and purpose to their lives. Similar findings were discussed by Wright-St Clair, Kerse and Smythe (2011) in research undertaken in New Zealand, here the focus was on occupation and included the more broad definition of it as the everyday activities that are ordinary and familiar to participants. Their qualitative study used phenomenology as a way to bring attention to “everyday modes of existence” (Wright-St Clair et al., 2011, p. 89), including occupation while being aged. In the study 15 participants, who were aged between 71-97 years, spoke of the importance of “doing the routine, always-there things in their day and of doing deeply purposeful things” (Wright-St Clair et al., 2011, p. 91). These activities gave a sense of “higher life satisfaction” for participants (Wright-St Clair et al., 2011, p. 93).

For people with long-term conditions work has been shown to provide other health benefits. In a longitudinal study over seven years Gruenewald, Karlamangla, Greendale, Singer & Seeman (2007) spoke to 1,189 people aged between 70-79 years and found that older people had better health outcomes, such as ability to perform activities of daily life (bathing, grooming, dressing, eating etc.), if they regularly felt useful to others. Similar results were found by Musick and Wilson (2003) in that those who participated in work, either volunteering or paid, had less symptoms associated with depression. Several authors also discuss that participants have a more positive view of life and higher life satisfaction if
In the past PD has been viewed as a condition more likely to be seen in retired people or that people would take retirement early if diagnosed (Simpson, McMillan, & Reeve, 2013). More recently, due to improved medication, earlier diagnosis and changes to the perception of when a person should retire, people are now continuing their working lives while undergoing treatment for PD. In New Zealand, while there is no longer a defined retirement age, many consider 65 years to be when formal work will cease as this is when most people become eligible for state-funded superannuation payments. Therefore, there can be several years in which a person with PD will continue to work. These people are the focus of the thesis reported here.

**Working while having Parkinson’s disease**

While life with PD can be unpredictable (Holmes et al., 2013), several authors agree that working may improve the QoL for people with PD. Researchers have shown that work helps people with PD feel more in control of their lives as well as their bodies (Benharoch & Wiseman, 2004; Holmes et al., 2013; Kang & Ellis-Hill, 2015). Further to this, the nine female participants in Olsson and Nilsson’s (2015) qualitative study spoke of improved feelings of wellness if they worked for employers who had faith in their work.

Research that directly addresses working with PD includes Benharoch and Wiseman (2004) and Thordardottir, Nilsson, Iwarsson and Haak (2014). Benharoch and Wiseman (2004) used semi-structured interviews of eight participants to ascertain the importance of participating in work for people with PD. Their qualitative study reported that many of the participants had difficulties with activities in their daily lives such as washing, dressing and grooming and they also found work more of an effort. Five of the eight participants in the research had either left work or had symptoms bad enough that they now considered themselves unable to work (Benharoch & Wiseman, 2004). For those able to work it was seen as being beneficial. For example, one participant said that “I carry on with my job at work, it keeps the brain active” (Benharoch & Wiseman, 2004, p. 383).

Qualitative research undertaken by Thordardottir et al. (2014) utilised focus groups where 29 people with PD discussed participation in daily activities, including work, after a diagnosis of PD. The authors found that the visibility of symptoms such as a tremor or difficulty walking, commonly inhibited full participation in work, but that it was the severity of symptoms that
inhibited people the most. Participants also indicated that the unpredictable nature of PD symptoms, such as falling or freezing, increased feelings of uncertainty and they were reluctant to engage in work or social events (Thordardottir et al., 2014).

In contrast Kang and Ellis-Hill (2015) found that physical limitations did not impact on the participants’ feelings of living successfully with PD. The authors focused on how the participants perceived living successfully with the condition. They argued that it was more the participant’s ability to live as normal a life as possible that meant they viewed it as being successful. The five participants had been living with PD from between 2-16 years and had a range of severity to their symptoms, although all had a certain level of physical symptoms such as tremor or gait disturbance. Participants described successful living by comparing their pre-PD life to that after diagnosis. Focus was given to their physical appearance and being able to undertake their usual routines. For one participant being able to maintain part-time employment was an indicator of living successfully (Kang & Ellis-Hill, 2015).

**Depression in long-term conditions**

Evidence suggests that adults with long-term conditions are twice as likely to have depression than those without them (Aragones, Pinol, & Labad, 2007; Moussavi et al., 2007). Depression has the largest effect on worsening mean health scores when adjusted for socioeconomic factors and health conditions (Moussavi et al., 2007). Depression can also be overlooked as difficult to treat for those with long-term conditions as it can be normalised by health practitioners and seen as being a part of a disease (Coventry et al., 2011).

Although there are physiological causes for depression in some long-term conditions, this is not always the case (Patten et al., 2005). Depression and long-term conditions often occur together for many reasons because, as a participant acknowledged in the Coventry et al. research, the diagnosis of a long-term condition “upsets your equilibrium, it upsets the way you see yourself, you lose your autonomy in terms of your health” (2011, p. 3). Furthermore, clinicians admit that it is often difficult to differentiate between a patient’s general health and their mood (Coventry et al., 2011) and indeed depression can go unrecognised by some clinicians (Piek et al., 2012).

**Depression in Parkinson’s disease**

Depending on the criteria used depression can affect between 2.7%-90% of people with PD (Reijnders, Ehrt, Weber, Aarsland, & Leentjens, 2008). The disparity of numbers is accredited to the different methodology used in research into the subject, which includes little
information given about how cases were identified, the description of PD diagnosis and the criteria used for depression (Reijnders et al., 2008). For people with depression and PD, there are both psychological as well as physiological causes (Chaudhuri, Healy, & Schapira, 2006). Psychological causes may include adjusting to the condition and the sense of uncertainty the condition can bring to people’s lives (Hurt, Weinman, Lee, & Brown, 2012). Physiological causes are attributed to damage to the serotoninergic neurotransmission as well as limbic noradrenergic and dopaminergic mechanisms leading to neurobiological changes in the brain (Chaudhuri et al., 2006). Most research into the subject focuses on the effect it has on a participant’s QoL with researchers agreeing that depression in PD affects a person’s QoL and for some it is a stronger predictor of low QoL scores than motor-symptoms (Hammarlund, Hagell, & Nilsson, 2012; Muller, Assmus, Herlofson, Larsen, & Tysnes, 2013).

**The meaning of fatigue in long-term conditions**

Although the concept of fatigue can be difficult to describe, as it is a subjective experience, it is viewed as being distinct and more than tiredness (Tralongo, Respini, & Ferràü, 2003; Zwarts et al., 2008). Fatigue is often described as exhaustion, lack of energy, weakness and strain (Tralongo et al., 2003; Zwarts et al., 2008). Lerdal, Celius, Krupp and Dahl define fatigue as a “sense of exhaustion, lack of perceived energy and tiredness” (2007, p. 1338). It is common in the general population (Lerdal, 2005) and is also a side-effect of many conditions including multiple sclerosis (Lerdal et al., 2007), HIV (Lerdal, Gay, Aouizerat, Portillo, & Lee, 2011), chronic kidney disease (Bonner, Wellard, & Calatabiano, 2010), stroke (Lerdal & Kottorp, 2011), pulmonary disease (Small & Lamb, 1999) and cancer (Tralongo et al., 2003) as well as PD (Elbers, van Wegen, Verjoe, & Kwakkel, 2008; Herlofson, Ongre, Enger, Tysnes, & Larsen, 2012).

Lerdal (2005) argues that having energy to perform daily tasks is highly valued in society as it is the basis for independent life and is linked to favourable self-image and self-esteem. Some research reports that fatigue interferes with people’s lives more than their conditions as it limits their ability to function normally in society (Zwarts et al., 2008). One participant in the Zwarts’ (2008) study described the symptoms of their condition as being quantifiable, whereas fatigue was not, thus it interfered more in their daily life.

The experience of living with fatigue and a long-term condition remains largely under-reported in favour of a biomedical focus on cause and treatment (Kralik, Telford, Price, & Koch, 2005). What is reported shows that fatigue disrupts all aspects of participants’ lives and it produces feelings of uncertainty as it throws “assumptions, predictability and planning
into turmoil” (Kralik et al., 2005, p. 375). Furthermore, for women with fibromyalgia, fatigue emphasised the experience that their bodies were a burden and that it was unpredictable, exacerbating the lack of control they felt they had over their illness (Söderberg & Lundman, 2001).

**Fatigue in Parkinson’s disease**

As discussed, fatigue is a side-effect of many long-term conditions, including PD. It is present in approximately 50% of people with PD and can be seen as a symptom of PD without relation to other motor symptoms (Herlofson & Larsen, 2002; Herlofson et al., 2012). The symptom often appears early in the progression of PD, rather than as a result of extensive cell death (Herlofson et al., 2012). Fatigue affects the QoL in health-related outcomes in that it increases distress in the lives of people with PD (Elbers et al., 2008; Herlofson & Larsen, 2003), it means they cannot carry out their everyday activities (Herlofson et al., 2012) and that they withdraw from work, family and their social lives (Herlofson & Larsen, 2002).

The impact and meaning of fatigue can also go beyond affecting the QoL for participants by emphasising their loss of body control and that the body may be seen as a burden (Olsson, Stafström, & Söderberg, 2013). In the presence of fatigue the body behaves differently, it will not fulfil its normal daily activities and becomes a barrier to normal life (Olsson et al., 2013). The 11 women in the Olsson et al. (2013) study spoke of having to make constant adjustments and that they lost a sense of security of what their bodies were capable of doing.

The findings that the body may be seen as a burden, and is out of control, mirror those found by researchers in regards to other symptoms of PD, as well as fatigue (Olsson et al., 2013). The experience of living with a range of PD symptoms will now be discussed further in this literature review. To begin, the research that takes a more general approach will be reviewed.

**The experience of living with Parkinson’s disease**

Research into the experience of living with PD is diverse. Many aspects of these peoples’ lives have been researched, both particular elements such as living with deep brain stimulation or gait disturbance, as well as research that takes a more general view into the experience of living with PD. In the following section focus will be given to both the broad research as well as the experience of living with particular elements of PD.

Results from the broad view research indicates that, just as with other long-term conditions, people want to know that healthcare providers have some sense of what it is like to live with PD (Holmes et al., 2013). In a review of literature Holmes et al. (2013) focused on the
experience of living with PD and presented key overall findings. The authors reported that the unpredictable nature of PD affected people’s ability to maintain family, social and work responsibilities. Focus was on scheduling and management of medication. Furthermore, fatigue was seen to impact on their lives both physically and cognitively (Holmes et al., 2013).

In other research authors emphasised the changes a person with PD may experience in relation to restrictions in their bodies but also that people with PD do not want to be viewed solely as having the condition (Haahr, Kirkevold, Hall, & Østergaard, 2011). In the qualitative study by Haahr et al. (2011), 11 participants took part in interviews which focused on the experience of living with late-stage PD. The authors found that it was important to participants that rather than being seen as a set of symptoms to be managed, they were viewed as a whole person, engaging with healthcare providers on many levels (Haahr et al., 2011).

There is also research that focussed on how people with PD see themselves as living successfully. From the eight participants in their research Kang and Ellis-Hill (2015) demonstrated that if they were able to maintain their usual life and physical ability they saw themselves as living successfully. The researchers described a ‘circle of successful living’ that involved a usual state of health and then a readjusted state of health. This circle was constantly changing as PD symptoms worsened but participants spoke of feeling their lives were most successful if they were able to manage this constant change in their lives (Kang & Ellis-Hill, 2015).

Managing the constant changes in a participant’s life when they have PD is the central theme in other research as well (Bramley & Eatough, 2005; Stanley-Hermanns & Engebretson, 2010; Williams & Keady, 2008). Stanley-Hermanns and Engebretson (2010) used the metaphor that likened the journey for participants as that of a sailing ship in a storm, with the ship representing the participant’s body and the storm the impact of PD. Participants are held captive by an uncertain, deteriorating vessel but also imprisoned by the storm, they searched for calmer water at the same time begin adapting to the voyage (Stanley-Hermanns & Engebretson, 2010).

In the single participant study undertaken by Bramley and Eatough’s (2005), PD disrupted the participant’s sense of autonomous self in that her body no longer represented how she saw herself. The body would not move as it once would, it would jerk or freeze or fall, and
the participant spoke of feeling embarrassed by her body (Bramley & Eatough, 2005). Although there was only one participant in their research, the researchers gathered extensive data during three semi-structured interviews. Furthermore, using the methodology of interpretative phenomenology ensured the data were analysed with great depth.

Where the research discussed above took a general view, there is also research that focuses on a particular aspect of a person’s life when they live with PD. This research includes the topics of freezing and gait disturbance; communication changes; sleep disturbances; bowel and bladder changes; deep brain stimulation and shame. Each of these aspects will now be explored. As with the broad research into the experience of living with PD, these elements also support an overall theme that for people with PD they not only lose a sense of control of their bodies but they also become controlled by the body as it is lost to the condition. Life becomes bound with symptom management and there are changes to the relationship between the body and self (Habermann, 1996).

**Freezing and gait disturbance**

Brichetto, Pelosin, Marchese & Abbruzzese (2006) describe freezing as a sudden and short-lasting break to voluntary movement. It frequently occurs in people with PD, affecting 7% of people in the early stage but rising to 60% in those with advanced PD (Bartels et al., 2003). Several quantitative studies exist that examine the relationship between freezing and falls (Lewis & Barker, 2009; Moore, MacDougall, & Ondo, 2008); the relationship between freezing and other PD symptoms (Bartels et al., 2003; Giladi, Shabtai, Rozenberg, & Shabtai, 2001) as well as ways to overcome it (Ottosson, Lavesson, Pinzke, & Grahn, 2015).

The research identified in regards to qualitative research into freezing and living with PD tells us that freezing is connected to a person’s physical, psychological and emotional selves (Hammarlund, Andersson, Andersson, Nilsson, & Hagell, 2014). Eleven participants in the Hammarlund et al. (2014) research spoke of the emotional and social consequences, along with a loss of independence, that occurred due to problems with gait. Feelings of sadness and hopelessness were described by participants when they had walking difficulties, as were feelings of panic and powerlessness. These findings are similar to those found in the Bramley and Eatough’s (2005) research. Here the participant also expressed feelings of humiliation when she fell or had episodes of freezing, and for her this increased her feelings of social pressure.
Because the experience of freezing can vary between each person with PD in regards to its frequency, duration and time of day it occurs, Redmond and Suddick (2012) argue that for some it can become an entity unto itself. The researchers used an interpretive phenomenological approach and interviewed six participants who all experienced freezing and gait disturbances. For some freezing occurred occasionally, only once or twice a month, but for others it was up to ten times a day. Participants in the study spoke of freezing heightening the link between their emotional and physical selves because it was unpredictable. Freezing also emphasised their feelings of alienation in their bodies as they felt separate from them. Once an episode of freezing had passed, participants spoke of feeling happy as they were able to “get things done” and “felt alive again” (Redmond & Suddick, 2012, p. 172).

The lack of connection with their body, of it being out of their control and unfamiliar, mirrors findings in other PD research; the experience of living with communication difficulties and shame in their bodies are other components of PD that have been researched and similar findings emerged.

**Communication changes**

Communication changes, including changes to voice and speech, occur in 70-90% of people with PD (Miller et al., 2007; Miller, Noble, Jones, & Burn, 2006). Changes include loss of volume, difficulty articulating certain sounds, loss of variation in pitch and changes to language use (Miller, 2012). As well as this, non-verbal gestures become difficult as hand gestures are limited and a loss of facial expression reduces comprehension by others (Miller, 2012).

The changes to people’s ability to communicate can have a profound effect on their capacity to interact with the world and be understood. Findings indicate this loss is experienced as negative by people with PD as it is associated with feelings of incompetency and inadequacy (Miller, Andrew, Noble, & Walshe, 2011). Thirty seven participants in the qualitative study by Miller et al. (2006) spoke of being frustrated by being misunderstood or experiencing the impatience of listeners as they waited for sentences to be finished (Miller et al., 2006). In response, both studies found, some participants withdrew from social interaction or tried strategies to try to overcome the loss (Miller et al., 2011, 2006).
**Sleep disturbance**

As a side-effect of PD, sleep disturbance was first reported as early as James Parkinson’s original research into the condition (1817/2002). Assistants of Parkinson noted of a patient at night that “…of late the trembling would sometimes begin in his sleep, and increase until it awakened him: when he always was in a state of agitation and alarm” (Parkinson, 2002, p. 226). Sleep disturbance can affect the QoL and daily functioning of those who experience it (Aitken, Naismith, Terpening, & Lewis, 2014; Gunn, Naismith, Bolitho, & Lewis, 2013; Mitra & Chaudhuri, 2009). Sleep is important for memory, neuropsychological functioning as well as having other physical and psychological benefits (Gunn et al., 2013).

Sleep disturbance is reported in 60-90% of those who have PD (Mitra & Chaudhuri, 2009) but most of the research has focused on prevalence, signs and symptoms as well as its cause (Aitken et al., 2014; Gunn et al., 2013; Mitra & Chaudhuri, 2009) rather than the experience of living with sleep disturbance. In comparison, Suddick and Chambers (2010) explored the experience of living with sleep disturbance while having PD. For the five male participants, sleep could be good or bad in quality and this added to the feelings uncertainty in their bodies. Participants expressed feelings of loss with regard to sleep disturbance: loss of control over sleep, loss of sleeping in the marital bed, and loss of work and hobbies (Suddick & Chambers, 2010).

**Autonomic changes**

While PD is often described as a movement disorder with movement-loss a primary symptom, there are also a range of autonomic changes that occur in people with the condition. Autonomic changes were once described as being part of the late-stage of PD, but this view has changed and it is now considered that they are part of the whole sequelae of PD. They often start in the early stages of PD and continue through the progression of the disease (Jost, 2010).

The effect on the QoL for people with autonomic changes is rarely considered in research, but it is believed that nearly all of those with PD experience changes in some form (de Luka, Svetel, Pekmezović, Milovanović, & Kostić, 2014). These changes include orthostatic dizziness, bladder dysfunction, weight loss, excessive or insufficient salivary production, dysphagia, nausea, decreased bowl motility and erectile dysfunction (Lawrence, 2015; Magerkurth, Schnitzer, & Braune, 2005)
Both Magerkurth et al. (2005) and Lawrence (2015) argue that these changes have a profound effect on people’s lives. Their research focuses on bowel and bladder changes specifically, but other research examined the changes to QoL with other autonomic dysfunction with PD (Muller et al., 2013; Santos-García & De La Fuente-Fernández, 2013). In Lawrence’s (2015) thesis the author argues that there is generalised feelings of shame felt in the population about bowel and bladder dysfunction, and that it is experienced by people with PD as well. The research utilised quantitative surveys as well as semi-structured interviews which focused on the symptoms as well as their management. Lawrence (2015) reported that whilst participants had low to moderate levels of QoL disruption due to bowel and bladder changes, the actual impact on their lives was expressed as being far more severe. Participants spoke of finding it difficult to get to the toilet in a timely manner due to their motor movement difficulties and this accentuated their experience of dysfunction. They also withdrew from social events as they lacked the financial resources to use products needed when a person has bowel and bladder dysfunction. Furthermore, disease management felt almost like a full-time job and they spoke with grief that it was robbing them of the life they thought they were going to live (Lawrence, 2015).

Research into the impact of other autonomic changes focused on the effect the symptoms have on QoL. In Spain, Santos-Gracia and Fuente-Fernandez (2013) used questionnaires to investigate the perceived QoL of 150 people with PD. The authors focused on non-motor signs, such as constipation, nocturia, difficulty swallowing and forgetfulness, and found that these impacted on both health-related and perceived QoL for participants. These findings were also supported by Muller et al. (2013). Again in this research questionnaires were used to ascertain the impact of motor vs non-motor symptoms but their focus was on QoL in early PD. Of the 188 participants it was widely agreed that non-motor symptoms such as fatigue, depression and sensory complaints had the most bearing on QoL (Muller et al., 2013).

**Shame**

The feeling of shame can occur in a range of situations and occasions in life (Lewis, Haviland-Jones, & Barrett, 2008) and can be part of the illness experience for many. Research into the experience of living with symptoms of PD has shown that shame and guilt are often associated when symptoms are visible in the public (Caap-Ahlgren, Lannerheim, & Dehlin, 2002). In the qualitative study by Caap-Ahlgren et al. (2002), researchers used interviews from eight women who expressed feelings of shame and guilt at their appearance.
They also felt stigmatised as they lacked facial expression and struggled to walk. Participants worried people would wonder what was wrong with them (Caap-Ahlgren et al., 2002).

The findings of Caap-Ahlgren et al. (2002) mirror those of much earlier research by Nijhof (1995) which explored the life story of 23 people with PD, 12 of whom spoke of PD as “a problem of shame” (Nijhof, 1995, p. 193). Participants often felt embarrassed by their symptoms, such as their difficulty with speech or their need for help with daily activities (Nijhof, 1995). They also felt shame when they felt people staring at them or when they felt like a “little old woman” (Nijhof, 1995, p. 196) who needed help. This sentiment was shared by participants in the Caap-Ahlgren et al. (2002) research who enjoyed contact with people who saw them just as they are. One participant spoke of grandchildren who did not ask many questions and just entered a room and said “hello Grandma!”

*The experience of deep brain stimulation*

With prolonged use levodopa reduces in effectiveness (Horstink et al., 2011). When this occurs surgery is considered to decrease the symptoms of PD. There are several different surgery options considered, including neuroblative lesion surgery to the thalamus or globus pallidus or, more commonly, deep brain stimulation (Bronstein et al., 2011).

Deep brain stimulation utilises the implantation of an electrode into the target site which is then connected to a pace-maker device located under the clavicle (Groiss, Wojtecki, Sudmeyer, & Schnitzler, 2009). Whilst the exact mechanism of how deep brain stimulation works is not fully understood, it is believed that overactive neuronal circuits are disrupted which allows for normal circuitry to improve motor control (Groiss et al., 2009). The improvement to motor-control can lead to a significant reduction of medication however; non-motor symptoms remain unaffected or can worsen (Bronstein et al., 2011).

In qualitative research into the experience of deep brain stimulation Haahr, Kirkevold, Hall and Østergaard (2010) drew on the hermeneutic phenomenological methodology of van Manen. The authors demonstrated that patients experience three phases as they adjust to the results of the surgery. These stages include feeling liberated as the symptoms were greatly reduced; that the change produced more challenges and finally that life with PD needed to be re-defined (Haahr et al., 2010). The nine participants in this research had a mean duration of disease of 15 years and ranged in age from 47-67 years. All had been prescribed levodopa to manage PD symptoms, but this had begun to decrease in effectiveness. After the deep brain stimulation participants spoke of their ability to walk unaided, or to stay up later at night.
Many experienced a higher level of independence. They no longer had to plan ahead so much and worried less about the future. One participant said that they were “living in the present and making the most of what I have got” (Haahr et al., 2010, p. 1233).

**Late-stage Parkinson’s disease**

As PD advances the complex range of symptoms become more pronounced and difficult to control (Hassan et al., 2012). People may begin to experience longer periods of dyskinesia, an increase to involuntary movements and episodes of freezing may become more pronounced (Haahr et al., 2011; Hassan et al., 2012). Additionally, the role of care-givers can change during this period as a person with PD becomes more reliant on others for help with daily activities (Hasson et al., 2010; Horstink et al., 2011). As with other aspects of PD, late-stage PD can mean making constant adaptions as life changes but at the same time, people try to hold on to their old life for as long as possible (Haahr et al., 2011; Sunvisson, 2006; Whitney, 2004; Williams & Keady, 2008).

Using the methodology of interpretative phenomenology, Whitney (2004) sought to better understand how older people with PD maintained QoL. The choice of interpretative phenomenology was made as it is a way participants could use storytelling to “describe and reconstruct past experiences” (Whitney, 2004, p. 30). The author took one story from a participant to develop the metaphor of ‘maintaining the square’, in reference to her enjoyment of square dancing. After interviewing 12 participants, this metaphor was used to capture the five themes described by the author because it centred on maintaining their world for as long as possible. These themes were: learning how, accepting limitation, seeking knowledge, engaging in meaningful experiences and living for today. Whitney argues that PD causes a sense of disruption to the lives of people who have it, but that this disruption can be decreased if they are able to have continuity in their lives. The author suggests that nurses and other healthcare professionals learn what activities and relationships are important to people with PD and encourage ways for these to be maintained (Whitney, 2004).

Building on the work of Whitney (2004), Williams and Keady (2008) used the image of ‘bridging’ as a way to describe what they understood from 69 interviews with 13 people with PD and their caregivers (n=26). ‘Bridging’ had three parts: building on the past, bridging the present and approaching the future. Importantly, the past included self-identity and life history, the present was focused on maintaining stability and protecting routine and the future centred on coping with fatigue and a collapse to stability. As with the Whitney (2004) research, ‘bridging the present’ included maintaining daily activities and interests, something
that was also difficult for the participants but ultimately enabled them to hold on to self-
identity (Williams & Keady, 2008).

Finally, the sole participant in Sunvisson’s (2006) research spoke of a shift from control to a
loss of intentional skills. The study was undertaken over a five year period and the 12 hours
of interviews that made up this study show a depth of findings rarely seen in PD research.
These findings track the continued decrease to the participant’s sense of self and happiness in
her body. Life became focused on her lost sense of control over her daily life. Movement
shifted from intentional to ones that required deep concentration. The participant used eating
as an example, where once she was able to do this without thinking, now each movement
must be concentrated on “otherwise the trout comes in wrong” (Sunvisson, 2006, p. 94).

The experience of living with PD means a constant struggle to adapt to a changing body and
a changing life. As participants expressed in many of the studies discussed, life became a
search for new meaning, but also an appreciation of what they have. PD is an intrusive
illness, one that makes those who have it aware of its presence (Whitney, 2004). PD can
mean a person’s lifeworld changes (Haahr et al., 2011). There are several symptoms that limit
normal day-to-day functioning for those who have them but participants regularly found once
acceptance of this occurred, there was new appreciation of their lives. The condition,
however, leads to constantly changing symptomology with appropriate medication changes to
match. Living successfully with PD means being aware of these changes and constantly
adapting to them as a way to hold on to identity.

**Osteopathy: Beliefs in healthcare**

To conclude this literature review a brief discussion on osteopathy, as well as a presentation
of research that includes the treatment of PD with osteopathy, will be undertaken. Whilst this
study is not directed specifically at osteopaths, but instead to healthcare providers in general,
it is undertaken by a student of osteopathy.

Osteopaths have long taken a broad approach to people’s health. This means that a person is
seen in a wider context, including not only their physical self but also their mental, social and
spiritual selves as well (Chila et al., 2011). The osteopathic philosopher Korr wrote of the
unity of the person, that their physical manifestations merely represent a part of a whole
(Parsons & Marcer, 2006). Korr believed that a well-rounded osteopath should look beyond
the presenting complaint and include the person’s experience and knowledge when making
treatment plans (Chila et al., 2011). As discussed, people with PD have spoken of wanting
healthcare providers who took an interest in or had prior knowledge in what their lives were like (Thorne et al., 2003). If osteopaths continue to follow in the traditions set out by Korr, then it is likely that a patient will indeed experience a practitioner who has an interest in and prior knowledge of the experiences they have in living with the long-term condition.

Additionally, it has been discussed by authors that people should not be seen as symptomatic problems to solve and that practitioners need to ensure they do not dehumanise them, as this leads to a lack of empathy (Nelson & Glonek, 2007). This view borrows directly from the philosophies of the founder of osteopathy A.T. Still, particularly from the book ‘Osteopathy: Research and Practice’ (1910). Still (1910) discussed not just treating a range of symptoms as this may mean missing the root of an issue and also disconnects the practitioner from the person. Whilst osteopathy can by no means cure or resolve PD, its focus on the patient, not just the symptoms, may help a patient to feel they are being seen as a whole person.

There is little research into the effectiveness of osteopathy to benefit people with PD, with most focused on correlating general osteopathic techniques to people with PD rather than undertaking studies on its effectiveness specifically (Fraix, 2012; Yao, Hart, & Terzella, 2013). Authors have applied osteopathic philosophy in order to encourage practitioners to use different models of treating patients with PD (Chila et al., 2011; Yao et al., 2013).

Osteopathic techniques are often aimed at treating a range of areas including the respiratory system, autonomic system and cardiovascular system (Chila et al., 2011; Yao et al., 2013). As indicated in the literature review, these systems can be affected by a range of symptomology with PD. Few studies exist that discuss the effectiveness of the treatment to these areas in regards to PD, however, there is evidence that argues its effectiveness in regards to general health. These studies can be applied to using osteopathic techniques to better the function of the health of people with PD.

Research into the use of gait training alongside osteopathy in the cranial field showed positive results (Müller & Pietsch, 2013). Here therapists used gait training alone, osteopathy in the cranial field alone and a combination of the two approaches as their three participant groups. Data were then recorded on the effect this had on gait over a ten metre distance. Gait training decreased the number of steps it took to cover the ten metres and osteopathy in the cranial field decreased the interval between steps. So in combination both approaches improved certain aspects of gait. The study was small, however, with 18 participants and the authors acknowledge that due to its structure, the participants could not be blinded. It was undertaken over two treatment sessions, with no longitudinal results taken. The authors
stressed that the results were only a change to symptoms, and no conclusion on the effectiveness of osteopathy treatment to treat PD was made (Müller & Pietsch, 2013).

**Summary**

Research into the experience of living with the variety of symptoms that occur with PD reveal that these have a profound effect on how a person experiences their world. Participants spoke of having to make constant adaptions as their bodies changed, of shame and of the loss they felt for the life they thought they were going to live. By continuing research into living with PD, it is believed that a focus can be given to providing more patient-centred care in that the options, values and experiences of those who have the condition can be voiced.

The aim of the current study was not to provide additional research into the efficacy of osteopathy technique for those who have PD. Instead, it will add to the body of knowledge of remaining in the workforce after a diagnosis of PD in a bid to improve how not only osteopaths but all healthcare professionals interact with them. As has been shown, people want healthcare professionals who have a sense of what it is like living with long-term conditions. Furthermore, work is considered a valuable part of life for those with PD. In order for work to continue, it may be helpful to understand its importance for people with PD and make clinical decisions to support it.
Part One Chapter Three: Methodology and Methods

Chapter three outlines the methodology and method used during the study of the experience of staying in the workforce after a diagnosis of PD. Interpretive description continues to guide the processes undertaken in this chapter.

Methodology

Consideration of methodologies
The literature review revealed that while there has been much research into the experience of living with certain aspects of PD there has been little that focuses on working while having the condition. There has been even less research undertaken in New Zealand and, to date, no research has been found that uses a qualitative methodology to research PD in New Zealand. Therefore the subject is lacking in research. This lack of research leads to a search for a methodology that is able to examine a subject with a great level of depth (Thomas & Magilvy, 2011) but in an exploratory nature. Qualitative approaches allow for this level of depth but also acknowledge that the research is exploratory. While it is often the case that the number of participants in qualitative research is small this allows for a greater amount of information to be gathered. Thomas and Magilvy (2011) argue that whilst the findings from qualitative research can often not be generalised to other settings, they add to a body of knowledge on a subject and encourage sensitivity in a patient-focused setting. Qualitative research is also the only way to adequately capture true human experience as it is able to describe the multifaceted experiences of people in their natural environments (Broussard, 2006). For these reasons qualitative methodology was chosen for the study undertaken here.

Within qualitative research there are several differing approaches that can be utilised. These methods include grounded theory, ethnography, phenomenology and interpretive description. Each method varies in its focus and the type of findings it may reveal. In order to determine the appropriate research method for this study it was important to consider both the purpose of the research as well as the research question itself (Morse & Field, 1995). Below is a brief outline of approaches and why they were considered less suitable than interpretive description for this research.

Grounded theory is useful if the aim of the research is to describe and explain a phenomenon (Bassett, 2006). The method was inappropriate for this study, however, as, when the
phenomena themselves are not identified and described, the work of creating statements of explanation is arguably too early. Where grounded theory focuses on developing a theory, this study was more exploratory in nature and aimed to interpret people’s experiences.

Ethnography is often used when research is aimed at culture, as it looks for patterns and changes within phenomena (Silverman, 2006). Again, this was viewed as an unsuitable method choice as the intention was not to describe patterns or changes in the phenomenon of continuing to work after a diagnosis in PD because it is not currently well understood.

Finally, although phenomenology, a method which focuses on the meaning of an experience (Smythe, 2012) and can allow for an exploration of meaning and interpretation (van Manen, 1997), may have been considered an appropriate method choice, the need for clinically applicable findings steered the choice towards interpretive description.

The current study focused on the experience of continued employment after a diagnosis of PD. I emphasised questions around the experience of participants continuing to work after a diagnosis of PD, therefore a method that examined the subjective experience of the participant was deemed appropriate. The approach needed to have logic and structure, but allow for interpretation (Hunt, 2009). The method also needed to have a clear way to describe the theoretical forestructure of the researcher, so as to locate myself within the research as well as the world that surrounds it. Thorne describes theoretical forestructure as a way to recognise what influence the researcher has in the research (Thorne, 2008). Therefore, describing this influence is part of creating a strong piece of interpretive description research. As part of theoretical forestructure in a following section the theoretical baggage of the researcher will be outline. Finally, the methodology needed to generate clinically relevant findings (Thorne et al., 1997). Therefore interpretive description, a method developed by Thorne et al., (1997) and described by Thorne (2008), was reasoned to be most suitable for this thesis.

**Interpretive description**

Interpretive description is a relatively new research approach and was developed to better understand phenomena important to nursing, as well as other applied health professions. As a method it is practice orientated, health discipline specific and interpretive focused (Thorne, 2008). It enables researchers to identify themes that arise out of collected data and “acknowledges the constructed and contextual nature of human experience that at the same time allows for shared realities” (Thorne et al., 1997, p. 5). As the literature review revealed
there is a lack of research into the phenomenon of working after a diagnosis of PD. Thorne argues that interpretive description is an appropriate method to use when themes and patterns are not well documented because, rather than being purely descriptive, “associations, relationships and patterns” (2008, p. 50) may be described.

Thorne, Reimer Kirkham and O’Flynn-Magee describe interpretive description as a way to examine “the subjectivity of experience within the commonly understood and objectively recognised conventions…” (2004, p. 3). The approach fits with answering the question asked in this study as a small group of patients were interviewed wholly on their subjective experience of working while living with PD. While PD itself is recognised objectively in its conventions as it has recognisable symptomology which, although varies from patient to patient, fits within this objective bound. The participant’s experience of these symptoms and their lives differs greatly.

Thorne et al. (2004) also developed truisms that underpin the epistemology and philosophy of interpretive description. These truisms arose through the naturalistic inquiry of Lincoln and Guba (1985) and state that “…reality is complex, contextual, constructed and ultimately subjective” (Thorne et al., 2004, p. 5). Thorne et al. (2004) go on to argue that the subject and researcher influence each other and become inseparable as they interact together and because of this multiple realities can be encountered. Therefore, it was important to enter this study understanding the ‘theoretical scaffolding’ (Thorne, 2008) paramount to creating a strong study. Thorne argues that there are two key elements to theoretical scaffolding: the literature review, which has been outlined in the previous chapter, as well as understanding the position of the researcher within the study, which Thorne terms ‘theoretical baggage’. By outlining theoretical baggage, Thorne argues the researcher is able to “convey an integrity of purpose that will not be confused with misuse of methods or erroneous claims” (Thorne, 2008, p. 71).

**Theoretical baggage: Locating myself in the research**

The impetus for the study reported here began with reading research that explored the experience of living with other long-term conditions. In this research participants often expressed a feeling that researcher’s lose sight of what it is like to live with a long-term condition. While undertaking another assignment as part of my osteopathic training, it also became clear to me that, rather than an immediate cessation of their working life, people with PD are now able to continue to work after their diagnosis. These drew me towards a thesis topic that included these two elements. Being a student of osteopathy also shaped my
literature review, the study methods, the language used, and the articulation of findings, discussion and recommendations as these needed to be clinically relevant.

In the process of preparing, reading and developing questions for this study I became aware that I had specific knowledge and experiences that could influence how this occurred, my theoretical baggage. The knowledge included a belief that those with PD would be severely disabled by it and only be able to do a minimal amount with their days. Because of this I entered into the research feeling pity for people with PD. I also entered the research with a bias against the New Zealand health system and expected participants to have many examples where it had let them down. After the first interview I reflected on these issues in an audio recording taken immediately after the interview. I recognised that I used a certain tone-of-voice and question framing that would lead to participants being able to tell me about the negative parts of the healthcare system and expected them too. I also recognised that my tone-of-voice may display feelings of pity for the participant having PD. In a bid to minimise these after the first interview I ensured I used a more neutral tone-of-voice as well as question structure. A later review of subsequent interviews showed that these issues were no longer obvious. While beginning the data analysis process I carefully checked to see whether any data were compromised by my earlier stance, which it did not as participant one responded with positive answers to the questions that had a biased tone.

Interpretive description allowed for the topic of working after a diagnosis of PD to be examined for meaning and explanation. It also ensured clinically applicable implications were found, as description alone was not enough (Thorne, 2008). It was an appropriate choice of methodology and guided me through the many aspects of writing this thesis.

**Methods**

In the previous section the methodology used in this research study was discussed. The section below includes an outline of how the I undertook the research. Included in this is a description of how participants were recruited, how data were collected and analysed, and the steps undertaken to ensure rigour in the study. Finally, ethical considerations in the research are outlined.
Participant sample and recruitment
Consistent with the exploratory nature of the study, and the methods of Thorne et al. (2004) and Thorne (2008), a relatively small sample size was appropriate. Purposive sampling (Thorne, 2008) was used to recruit five participants for the study, as per the inclusion/exclusion criteria.

Inclusion and exclusion criteria

**Inclusion Criteria:**

- A formal diagnosis of PD was an inclusion criteria for participants
- Undertaking paid employment of no less than 24 hours per week. This criterion ensured that participants undertook enough work hours in their week that it was a significant part of their lives
- Consent to having the interview recorded, transcribed and used for the purposes of this research study

**Exclusion Criteria:**

- Working fewer than 24 hours per week in paid employment

Recruitment
Five participants were recruited through word of mouth and an advertisement placed in the *Parkinson’s New Zealand* newsletter (Appendix 2). Participants made direct contact through an email address attached to the advertisement and were then sent an information sheet (Appendix 3).

The participants
Five participants were interviewed for this study: four women and one man. A summary of participant characteristic is presented in Table One.

Table One: Participant summary

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Gender</th>
<th>Years since diagnosis</th>
<th>Type of work</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>59 years</td>
<td>Male</td>
<td>4</td>
<td>Qualified tradesman</td>
</tr>
<tr>
<td>2</td>
<td>65 years</td>
<td>Female</td>
<td>1.5</td>
<td>Social work</td>
</tr>
<tr>
<td>3</td>
<td>61 years</td>
<td>Female</td>
<td>8</td>
<td>Healthcare</td>
</tr>
<tr>
<td>4</td>
<td>61 years</td>
<td>Female</td>
<td>2</td>
<td>Office work</td>
</tr>
<tr>
<td>5</td>
<td>68 years</td>
<td>Female</td>
<td>5</td>
<td>Office work</td>
</tr>
</tbody>
</table>
Data gathering

Research method

The processes suggested by Thorne (2008) in regards to using interpretive description for data collection and analysis are discussed in this section.

Data collection

In order to gain knowledge relating to the experience of working after a diagnosis of PD, exploratory, in-depth and semi-structured interviews were undertaken. Interviews were deemed the most appropriate form of data collection. They allow for the subjective experience of those that experience the phenomena to be explored (Thorne, 2008). The aim was to focus on the topic of the research by asking how patients thought and felt about their experience of working after a diagnosis of PD.

Interviews were undertaken face-to-face as this was considered the most suitable form of data collection for the phenomenon. The interviews were semi-structured, in that there was a list of topics to cover, but the interview was allowed to flow as in a conversation rather than being overly structured. Topics were developed with consultation with supervisors as well as fellow researchers. The semi-structured interview also meant data could be gathered that may not have been initially requested. Open questions allow for a more organic account of a participant’s experience but by observing and managing the process it ensured the conversation stayed on topic (Tracy, 2012).

Participants were asked to recall their lives prior to diagnosis, what lead to diagnosis and how their lives and work have been since diagnosis, however, each interview was semi-structured and followed a different set of questions to match the flow of the interview.

Questions included broad topics such as:

- Tell me about your life prior to diagnosis?
- What lead to your diagnosis of PD?
- How has work been since your diagnosis of PD?
- Could you tell me more about how your colleagues have been towards you since you told them about your diagnosis?

The complete list of questions used is included (Appendix 4), but it important to note that others were asked during the interview.
Five interviews were undertaken and ranged in duration from forty to seventy minutes. Once the topics had been covered and the participants felt they had said as much as they wanted the interview drew to a natural ending. The five interviews used for this study lead to approximately two hundred and sixty minutes of interview time. The interviews then underwent a ‘sorting and organizing’ (Thorne, 2008) process which included transcribing and anonymising. The transcription was prepared by Scribie, a business that specialises in the transcription of audio files. Scribie signed a confidentiality agreement (Appendix 5). In order to increase confidentiality each recording was broken into small sections by Scribie which were then transcribed by different transcribers. Prior to being returned to the researcher these were then electronically re-assembled. Transcripts were then checked against recordings for accuracy. At the same time they were also anonymised which included the removal of aspects of the interview that could lead to the identifying of participants. The transcripts were then returned to participants for a final check. One participant wished to make changes to the transcript; this will be addressed in a following section.

**Data analysis**

The underlying technique for data analysis followed Thorne’s (2000, 2008, Thorne et al., 1997, 2004) interpretive description approach. Thorne (2008) argues that rather than using a step-by-step process, data analysis is more complex. Findings do not just “emerge” (Thorne et al., 2004, p. 11) from data, instead the data is subject to four main processes: understanding the phenomenon being studied, the synthesis of meaning, theorising about relationships within the data and then placing the data within the current knowledge on the phenomenon (Thorne, 2000, 2008; Thorne et al., 1997).

**Understanding the phenomenon being studied**

The process of understanding the phenomenon involves repeated immersion in the data so as to understand the settings or experiences of participants. The process is not done in a single step; instead it occurs during data collection and coding as well as with the questions a researcher constantly asks themselves in a bid to understand a phenomenon as deeply as possible (Thorne, 2008).

**Synthesis of meaning**

Here the researcher merges examples that describe characteristic patterns within the data. Common elements in the individual patterns are found in a bid to find features that are represented across the data (Thorne, 2008).
Theorising about relationships within the data

During the cognitive process of theorising about relationships, the how and why of relations within the data are explored (Thorne, 2000, 2008). Further questions can be put to the data here as well (Thorne, 2008).

Placing the data within the current knowledge on the phenomenon

By undertaking this process the researcher is able to fit the findings into other settings or contexts. Here, as Thorne (2008) describes, the theoretical can be brought back to the practical, as the implications of the new knowledge are realised.

Because the steps described above are interwoven, rather than taken one after another, the process undertaken in this thesis will be described below. As Thorne (2008) describes these often occurred concurrently rather than in a step-by-step process.

Immersion into the data began during collection. To align with Thorne’s (2008) suggestion of making ‘tracking reflections’, reflective recordings were made immediately after each interview. These included what was believed to be the primary themes from the interview but also any theoretical forestructure that may have occurred during the interview (Thorne, 2008). These notes formed the structure around which the ‘theoretical baggage’, outlined in a previous section, was created. The recordings were transcribed once the researcher was home and added to as necessary. The transcribed reflective recordings, as well as any additional written notes, became part of the reflective journal created as data analysis was undertaken.

Analysis continued subconsciously while the data were checked and anonymised after transcription. It then deepened with repeated listening to the recordings and reading the transcribed data. Notes were made during these steps, with reflections made on themes that were emerging, contradictions to emerging themes, outliers and other areas that could deepen the information being gathered (Thorne, 2008).

After listening to the interviews, and reading and re-reading the transcripts, colour-coding was applied to the emerging themes that appeared the most significant. This step brought out six recurring themes. Using a cut and paste method, key ideas or statements were then grouped and indexed into each theme. As an example, P1p1 stood for an idea that emerged from participant one and was located on page one of their interview. This step also led to an impression of the importance of a theme in that the amount of times a similar statement or idea was expressed during the interviews gave an indication of its importance.
Next mind-maps were created to represent each interview. Then another set were created to look for patterns across all interviews. These were colour coded, with certain colours matching certain themes (for an example, see Appendix 6).

The next step was to group sub-themes so that more overarching themes could be found. A subjective interpretation of meaning was explored here as often these were not taken from the literal words used by participants, but rather an underlying message was sort. These themes and subthemes were then discussed at length with supervisors and peers. Reflective journaling was used extensively during this step to question theoretical forestructure and assumptions (Thorne, 2008). Audio recordings were re-listened too and transcribed interviews re-read in search of occasions were participants disagreed with findings. Findings in this step were tentative and constantly question so as to avoid a misinterpretation of frequency as well as premature closing which Thorne (2008) argues can weaken the data produced in research. Once they were more concrete, another mind-map was created to represent the overarching themes found between the interviews. These steps brought out three major themes, each with several subthemes (Appendix 7). Next each theme and subtheme had relevant quotes placed with them and these were developed into the findings presented in the manuscript below. An example of this process can be seen in the appendices, with the third theme developed from ideas with quotes attached to the nearly complete theme (Appendix 9).

All stages of the data analysis process were recorded, either as an audio recording between the researcher and supervisors or as part of the reflective journal. In order to remain open to other interpretation Thorne’s argument that a researcher should constantly be asking “What am I seeing?” and “Why am I seeing it?” (Thorne, 2008, p. 158) was used to question findings. Breaks were also taken between analysis sessions, occasionally up to two weeks in length. These breaks meant that when the data were returned to ideas could be checked with a fresh mind which again strengthened the final findings.

**Ethical considerations**

Ethical approval was granted for this thesis by the Unitec Research Ethics Committee in September 2015 (Appendix 8). Areas of consideration for ethical approval were: protection, participation, withdrawal from study and partnership.
Protection
An information sheet regarding the study was given to potential participants (Appendix 3). They were also asked to supply informed consent with a consent form which was signed immediately prior each interview commencing (Appendix 10).

All audio data collected during the interviews, the transcripts, all emails as well as the thesis as it was written, have been stored in password protected computer files on a password protected computer. All hard copy documents and transcripts have been kept separately and held within locked filing cabinets to which only I had access. The consent forms are held within a locked filing cabinet at the Unitec Institute of Technology. All these items will be kept for five years following completion of the study which is in accordance with the regulations of the Unitec Institute of Technology. After five years, all computerised files will be deleted and hardcopies securely destroyed.

Confidentiality and anonymity have been maintained throughout the study by using various steps to ensure this process. This began with the transcripts being anonymised when they were returned after the transcribing process. This step included the removal of the participant’s name, name of family members, name of work place, job description, name of doctor and any other identifying elements. The transcribed and anonymised interviews were then returned to participants for their review. Participants were given two weeks in which to add or remove anything they did not want included. There were changes made to one transcript, with the participant requesting the text be changed to reflect less conversational language and more formal language, as well as some spelling and grammatical errors. This task was undertaken by the participant but did little to alter the information gathered. For example the participant removed sentences that began with ‘and’ and changed contractions such as ‘I’m’ into ‘I am’.

Participation
Interviews were undertaken at a location of the participant’s choice. All chose to have their interviews in their own homes. Each participant had the right to a support person, but this was on the understanding that the person did not participate or contribute to the interview. No participants chose to have a support person. Provision had been made for two interviews with each participant if necessary to ensure all topics were covered and to allow for slow speech. Again, this was not required. At any time the interviews could have been halted if the participant requested but none did. Interviewees were also closely monitored for tiredness and engagement in case a break was needed.
Withdrawal from study
Participants were informed of their right to withdraw from the study at several stages of the data collection process. Their rights were outlined on the information sheet and consent form, as well as at the beginning of each interview and, finally, when anonymised transcripts were returned to each participant for checking. Each participant was given two weeks from receiving their transcripts to withdraw after which time data analysis commenced and removing one participant’s data would have been problematic. No participant withdrew from the study nor requested withdrawal of their data.

Partnership
It was requested by several participants that the full thesis, as well as any work produced for publication, be emailed to them. This will be undertaken once the research is complete.

Addressing rigour in qualitative research
In order for research to be credible, rigour must be addressed at all stages of its development. In qualitative research rigour replaces validity and reliability used in quantitative studies (Roberts & Priest, 2006). This section discusses how rigour is addressed in this study. For methodology consistency the evaluation criteria for rigour described by Thorne (2008) has been used. These include “epistemological integrity, representative credibility, analytic logic, and interpretive authority” as well as additional criteria for applied health researchers “moral defensibility, disciplinary relevance, pragmatic obligation, contextual awareness and probable truth” (Thorne, 2008, p. 102).

Epistemological integrity
All qualitative research should demonstrate “epistemological integrity in the sense that there is a defensible line of reasoning from the assumptions made about the nature of knowledge through to the methodological rules by which decisions about the research process are explained” (Thorne, 2008, pp. 223–224). The nature of knowledge in the study reported here is that those who continue to work after a diagnosis of PD are the experts in the topic, and their stories are the data that needed to be collected to understand the experience. Thus, the careful collection of their stories is paramount, as was preserving their meaning. Both steps were undertaken in the study reported here.

Furthermore, there should be a clear link between the research question, methodological approach, methods and the findings as well as congruency with the epistemological standpoint of the researcher (Thorne, 2008). The rationale for the methodology is congruent
with the aims of the research study and these have been discussed in a previous section. The methods for sampling, data collection and analysis are congruent with the research question and my intent as the researcher.

**Representative credibility**

Representative credibility is achieved by aligning sampling of participants with the phenomenon under study. Using a relatively small sample size in the study here meant interviews could be in-depth and ensured a rich level of data were collected. As well as this the findings are not claimed to be widely applicable beyond the group under research, although readers may recognise similarities with other groups.

Support for representative credibility also came through affirmation of findings when shared with supervisors, other researchers and osteopaths. These affirmations showed the findings passed the “thoughtful clinician” test (Thorne, 2008, pp. 84–85).

**Analytic logic**

Interpretive description studies need to reflect an analytic logic that makes explicit the reasoning of the researcher and enables the reader to either confirm or reject the credibility of the study (Thorne, 2008). Thorne suggests the use of an audit trail as it provides a technique to ensure that there is evidence of the steps undertaken in a study, rather than just relying on assurance that the researcher has undertaken an “inductive reasoning process” (Thorne, 2008, p. 225). An audit trail is seen in this thesis by the inclusion of the outlined steps taken through the research project, from outlining the purpose of the study through to the data analysis process as well as my position (as researcher) in relation to the phenomenon. Audio and written reflections were also used while working with the data. There is an example in the appendices of two figures used as the themes developed. These figures give a more detailed description of a developing theme as it arose in an individual participant to being a theme reflecting the experiences of all participants (Appendix 6). There is also an example of extended findings in the development of one theme (Appendix 9).

**Interpretive authority**

In order to ensure a study is both trustworthy and moves beyond the theoretical forestructure of the researcher, interpretive authority must be established (Thorne, 2008). The aim of the study was to explore the experience of people with a diagnosis of PD who continued to work. In the research a balance between the researcher’s interpretation and the voice of the participants was aimed for. I was constantly mindful of the need to make sure the data, and
not assumptions, drove the analysis and interpretation. Furthermore, rather than finishing after the first ‘light-bulb’ moment in analysis, I continued to analysis the data in search of deeper meanings behind the words of the participants. Discussions with supervisors, who were both experienced in qualitative research and one in interpretive description, ensured there was not early foreclosure on analysis and interpretation (Thorne, 2008).

*Moral defensibility*

The component of moral defensibility describes how applicable the research question and findings are to applied practice disciplines. It also ensures that knowledge taken from research is not only necessary but also that there is a clear purpose in obtaining the knowledge. There must be a clear benefit to those who share their experience and it must not bring about a risk of social censure because the knowledge is shared with sensitivity (Thorne, 2008).

*Disciplinary relevance*

The usefulness of the study to osteopathy, as well as other health disciplines, is required to meet this element of rigour (Thorne, 2008).

*Pragmatic obligation*

Here rigour is strengthening in the presentation of findings that do not harm a particular group. Having reflected on pragmatic obligation any application of the findings from the study presented here would not be to the detriment of any individual or group (Thorne, 2008).

*Contextual awareness*

The perspective and interpretation of the data is guided by the social, disciplinary and historical context and must be acknowledged to strengthen rigour in research (Thorne, 2008). In the study presented here these elements were outlined in the ‘theoretical baggage’ outlined in a previous section. As well as describing my ‘theoretical baggage’, the context in which the findings were constructed was addressed. Findings presented in the thesis here should be considered in the context within which they were constructed as well as with consideration of my ‘theoretical baggage’.

*Probable truth*

Finally, Thorne (2008) considers that research findings are not completely valid, due to the procedures and practices being unable to fully account for the many notions of truth. By accepting this, the idea of probable truth can be used until it is challenged with further
knowledge. Within the strengths and limitations of the thesis reported here probable truth can be asserted.

Summary
Chapter three of this thesis discussed the methodology of qualitative research as well as the method of interpretive description. The chapter outlined the practical and theoretical steps used in the research as well as discussion of ethical considerations and rigour. Chapter three concludes part one of the thesis. Part two will present the findings as part of a manuscript written for submission to The Scandinavian Journal of Caring Sciences.
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Part Two: Manuscript

Note: This manuscript is prepared in accordance with The Scandinavian Journal of Caring Sciences (Appendix 1), which requires an abstract that summarises the aims, design, findings and conclusions in 300 words. The word limit for this journal is 5000, excluding tables and references. Although efforts have been made to keep this manuscript concise, it currently exceeds the word count as detail was required to expand areas. These will be trimmed prior to submission. It also uses the reference style Vancouver. All other formatting remains the same.
Keeping Working to Keep Working: Staying in the Workforce with a Diagnosis of Parkinson’s Disease

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Part Two: Manuscript

Keeping Working to Keep Working: Staying in the Workforce with a Diagnosis of Parkinson’s Disease

Abstract
Aims: There is a lack of knowledge about the experiences of people who continue to work after a diagnosis of Parkinson’s disease. The purpose of this study was to explore the experiences of a small group of participants who continued to work while living with Parkinson’s disease.

Design: A qualitative study using interpretive description. Purposive sampling via word of mouth as well as an advertisement in the Parkinson’s New Zealand newsletter was used to recruit five participants. Data were collected via semi-structured interviews and analysed thematically.

Findings: The findings showed that the participants were able to continue to work by making constant adjustments to their working conditions, their homes and by using other self-management techniques to continue to live the life they wanted.

Conclusions: Three themes were identified: ‘participating in work’, ‘trying to reinvent’ and ‘bridging past and future’. Each interwove into an overarching theme of ‘working to work’ in that participants still wished to participate in work but in order to do this had to make adaptations and use strategies to ensure work could continue. They faced an uncertain future and spoke of their past while looking forward with hesitation.

Keywords: Parkinson’s disease, lived experience, interpretive description, work, occupation, New Zealand
Introduction

Parkinson’s disease (PD) is a long-term neurological condition, highly prevalent worldwide as well as in New Zealand. It is the second most common neurological condition, after Alzheimer’s disease (1), affecting approximately seven to ten million people throughout the world (2). The number of people with the condition is known to be increasing, and set to increase further, with the general ageing of the world’s population (3).

Advances in medication have meant that many people with PD are often able to work for several years after diagnosis. Indeed work may become an important part of their continued engagement with what these people consider their normal lives. However, people with PD face not only continued physical changes due to their declining health and the continued need for adjustments to their daily life, they also face psychological hurdles as well, as living with the constant knowledge of a life-limiting condition can bring challenges. It is these elements that are the focus of this study, with the study question being: what is the experience of continuing to work after a diagnosis of PD? The current study aims to add to the body of knowledge on living with PD, with a particular focus on working after the diagnosis.

From the perspective of people with long-term conditions, such as PD, research has shown how they want their healthcare to be delivered (4,5). Utilising an archive of 3,500 qualitative, narrative interviews that covered 60 different health issues, Ziebland et al. (4) found eight aspects of healthcare valued by people with a long-term condition. Those of particular significance were involving people in decisions, being able to engage in difficult decisions and sharing information across multiple health services. Of relevance for the current study is that participants also discussed the importance of a practitioner having an understanding of how their lives were affected by an illness (4).

Work is defined as being different from occupation as work is not just tasks and activities that relate to leisure, productivity and self-care (6). For the purpose of this study work was defined as “employment in a formal, paid position” (7). It is argued that working while having a long-term condition improves quality of life as it helps people feel useful, engaged with life and gives a sense of continuity to their lives (8–10). In some studies people with PD expressed that work was seen as a way to feel more in control of their lives, as well as of their bodies (11,12).

Research has shown that it can be the visibility of symptoms and unpredictable nature of PD that means participants were reluctant to engage in work or social events (13). Nevertheless,
engagement with what participants viewed as normal activity was rated an important factor in living successfully with PD in research undertaken by Kang and Ellis-Hill (12). Findings from in-depth qualitative interviews with eight participants suggest that healthcare providers should work with patients to determine what their usual life is, be that working or other activities, and then support them to develop new ways of maintaining this (12).

One symptom common in people with many different conditions, as well as in the general population, is fatigue (14). Fatigue can be difficult to describe, as it is a subjective experience, but it is viewed as being distinct from, and more than, tiredness. Words such as exhaustion, lack of energy, weakness and strain are used to describe fatigue (15,16). Lerdal (14) argues that having energy to perform daily tasks is highly valued in society as it is the basis for independent life and is linked to favourable self-image and self-esteem. Some research reports that fatigue interferes with people’s lives more than their conditions as it limits their ability to function normally in society (15). One participant in the Zwarts’ (15) study described the symptoms of their condition as being quantifiable, whereas fatigue was not, thus it interfered more in their daily life.

Fatigue is present in approximately 50% of people with PD and can be seen as a symptom of PD without relation to other motor symptoms (17,18). Fatigue affects the quality of life (QoL) in health-related outcomes in that it increases distress in the lives of people with PD (19,20). It means they cannot carry out their everyday activities (18) and that they withdraw from work, family and their social lives (17). The impact and meaning of fatigue can also go beyond affecting the QoL for participants by emphasising their loss of body control and that the body may be seen as a burden (21). In the presence of fatigue the body now behaves differently, it will not fulfil its normal daily activities and becomes a barrier to participants normal life (21). The 11 women in the Olsson et al. (21) study spoke of having to make constant adjustments and that they lost a sense of security of what their bodies were capable of doing.

The findings that the body may be seen as a burden and is out of control mirror those found by other researchers in regards to symptoms of PD. Life with PD can be unpredictable and uncertain (11). Managing the constant changes in a participant’s life when they have PD is the central theme of several studies (22–24). Stanley-Hermanns and Engebretson (22) used the metaphor that the journey for participants could be seen as that of a sailing ship in a storm, with the ship representing the participant’s body and the storm the impact of PD. Participants are held captive by an uncertain, deteriorating vessel but also imprisoned by the
storm, they search for calmer water but also begin adapting to the voyage (22). For the one female participant in Bramley and Eatough’s (24) research, PD disrupted her sense of autonomous self in that her body no longer represented how she saw herself. The body would not move as it once would, it would jerk or freeze or fall, and the participant spoke of feeling embarrassed by her body (24). Although there was only a single participant in the research, the researchers gathered extensive data during three semi-structured interviews. Furthermore, using the methodology of interpretative phenomenology ensured the data were analysed with great depth.

Building on the work of Bramley and Eatough (24), Williams and Keady (23) used the image of ‘bridging’ as a way to describe what they understood from 69 interviews with 13 people with PD and their caregivers (n=26). ‘Bridging’ had three parts: building on the past, bridging the present and approaching the future. Importantly, the past included self-identity and life history, the present was focused on maintaining stability and protecting routine and the future centred on coping with fatigue and a collapse of stability.

The aim of this study was to address the lack of knowledge about the experiences of people who continue to work after a diagnosis of PD. In a bid to address this lack of knowledge a small group of participants were asked to discuss their experiences of working while living with PD.

**Design**

Due to the lack of research on this subject in New Zealand, a qualitative approach was chosen as it permits the collection of rich data that were both subjective and experiential in nature (25). The research was undertaken and guided by interpretive description (25,26). Interpretive description is useful when a subject is not well studied, as is the case with this study. The methodology needed to have logic and structure, but allow for interpretation (27). Furthermore, it needed to generate clinically relevant findings (26).

**Recruitment and participants**

Purposive sampling (26) was used to recruit five participants. Two were recruited through word of mouth, while the other three responded to an advertisement placed in the newsletter produced by the national organisation, Parkinson’s New Zealand. All five participants received an information sheet and signed a consent form. The inclusion criteria required all participants to have a formal diagnosis of PD and to work more than 24 hours a week. Table One outlines the demographics of participants.
Table One: Summary of participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Gender</th>
<th>Years since diagnosis</th>
<th>Type of work</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>59</td>
<td>Male</td>
<td>4</td>
<td>Qualified tradesman</td>
</tr>
<tr>
<td>2</td>
<td>65</td>
<td>Female</td>
<td>1.5</td>
<td>Social work</td>
</tr>
<tr>
<td>3</td>
<td>61</td>
<td>Female</td>
<td>8</td>
<td>Healthcare</td>
</tr>
<tr>
<td>4</td>
<td>61</td>
<td>Female</td>
<td>2</td>
<td>Office work</td>
</tr>
<tr>
<td>5</td>
<td>68</td>
<td>Female</td>
<td>5</td>
<td>Office work</td>
</tr>
</tbody>
</table>

Data collection and analysis

Data were collected during face-to-face interviews with participants in their own homes. The interviews took between 40 and 70 minutes. Broad questions were used to allow participants to discuss the area’s most relevant to them. The interviews were then transcribed verbatim prior to analysis.

Five interviews made up the data set. The interview transcripts were reviewed by the researcher for accuracy. During this process the transcriptions were also anonymised. Guided by Thorne’s (26) interpretive description approach to analysis, the data were then listened to repeatedly. Potential themes that emerged were noted and then the data re-examined to find instances where a theme was confirmed or not confirmed. During this iterative process all themes were noted and then examined for importance. Initially this occurred within individual interviews, and then across all interviews. Continued discussions with supervisors as well as peer researchers ensured developing ideas were well rooted in the data and not just a misinterpretation of frequency (26).

Next sub-themes were sought within each theme. These were placed into themes and arranged and re-arranged as the meaning behind them was sought. Once a picture of the themes and subthemes became clear, they were again discussed with fellow researchers and supervisors. One theme was discarded because it was not relevant to the study question. Again the data were returned to in order to more clearly answer the research question. Once another theme was found that answered the question, the importance of the disregarded theme was discussed resulting in two being included as they remained central to the experiences expressed by participants. In keeping with Thorne’s approach (26) these steps helped avoid premature closing.

Ethical consideration
Ethical approval was obtained from the institutional Research Ethics Committee. Particular emphasis was placed on physical and psychological safety of the participants, informed consent, confidentially and data security. These were addressed through the whole research process.

**Findings: Working to work**

‘Working to work’ was the overarching theme, which included three interwoven themes ‘participating in work’, ‘trying to reinvent’ and ‘bridging past and future’. These themes and their sub-themes are presented in Table Two. All data excerpts are followed by an identifying participant number and page reference.

**Table Two: Themes and subthemes**

**Keeping working to keep working**

<table>
<thead>
<tr>
<th>Theme 1: Participating in work</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subtheme: Still having something to offer</td>
</tr>
<tr>
<td>Subtheme: Managing to work</td>
</tr>
<tr>
<td>Subtheme: Feeling a sense of responsibility</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme 2: Trying to reinvent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subtheme: Creating routine</td>
</tr>
<tr>
<td>Subtheme: Making adaptions and using strategies</td>
</tr>
<tr>
<td>Subtheme: Managing symptoms</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme 3: Bridging past and future</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subtheme: Feeling the loss of old lives and future they expected</td>
</tr>
<tr>
<td>Subtheme: Fearing what may be to come</td>
</tr>
<tr>
<td>Subtheme: Ageing with a long-term condition</td>
</tr>
</tbody>
</table>

**Theme 1: Participating in work**

Continuing in established work ensured participants were able to engage with the life they had created. Work gave them a sense of purpose. Most, but not all, participants still enjoyed their work, noting that the symptoms of their PD did not necessarily limit their ability to work. Several participants had to develop strategies to ensure they were able to work, leading to the overarching theme of ‘working to work’. There was also a sense of obligation to employers, employees and family members to continue to work for as long as possible as they felt that responsibility continued irrespective of their diagnosis.
Still having something to offer

Regardless of their having PD, participants spoke of wanting to participate in work as they wanted to feel useful. Several participants indicated they still had something to offer. Furthermore, their work offered them a place they could be connected with their established lives and maintain social connections. Work was important for participants because it brought order, stability and a sense of purpose. It helped them maintain independence.

_I do not like to think of not working. I like to feel that I am contributing and that I am useful. My plan is to keep working as long as I can._ (P5:18)

It was noticeable that when talking about their work, several participants brightened up and spoke of their work with clear enthusiasm. It seemed a valued part of their identity that they did not want PD to encroach upon.

_I’ve got no desire to stop working yet. I enjoy my work so I want to keep working._

(P2:1)

Work was a key part of participants’ lives and they still felt they wanted to continue to do it. It added focus and direction but also meant participants felt they were still able to do some of the things they wanted.

Managing to work

This subtheme illustrates the self-management strategies used by participants to ensure they could continue to work. Many of the adaptions included changes to work hours, the type of work they did and using techniques to decrease stress. These were all undertaken so that participants could continue to work, as it was important to them. Several said they had changed working hours to coincide with times of higher energy levels.

_I stayed in the role I am in at work but I have cut down my hours... I now do 35 hours. So, I cut out an hour in the morning. I start at 9:30 instead of 8:30. It means I miss the traffic, means I can sleep a little longer and do some exercise._ (P5: 3)

Another technique used was to be highly prepared for their work days. Several participants also brought work home with them or made sure they were available to work on weekends so that they could keep on top of the work they had to do. Participant two explained that for her being organised was important. In part this was due to having finite energy, but it is also a way she was able to manage her fear of being seen as unwell.
I suppose I don’t want to be off at work... I’m there and I’m prepped... all the preparation's been done for today at the weekend. (P1:8-9)

All participants had made several adjustments to their lives in order to keep working. Because it was still important to them, they made changes to ensure they were able to continue doing it.

**Feeling a sense of responsibility**

Participants also expressed a sense of responsibility and this meant they continued to work. One participant felt a responsibility to continue to employ someone, another towards a husband who was unwell and a third because the family had financial strain.

*I don’t have any plans to stop at the moment. If anything, I’d knock the winters back, that’s all. But [employee] has a young family who relies on me to provide him work. He has a mortgage to pay.* (P1:22)

Work remained, for several participants, a continuing sense of responsibility to those around them, regardless of their diagnosis of PD.

**Theme 2: Trying to reinvent**

For people with health conditions such as PD creating routine, as well as using strategies and adaptions, meant they are able to continue to live the life they wanted (12). Routine can be a way for people to manage the challenges they face. Adaptions ensured participants were able to continue their established lives and also feel they have a certain amount of control over some of their experiences. People with a long-term condition may feel they have little or no control over certain aspects of their experience such as access to healthcare, medication, side-effects or prognosis, but they are able to have some control in other aspects of their lives, such as work (28).

**Creating routine**

One method used to create a sense of control for participants was to use routine to order their days. In part, order is particularly necessary for people with PD as medication is carefully timed to avoid symptoms of the condition. Participants indicated that creating a routine was a strategy that supported their participation in activities important to them as it helped them cope with stress and meant they could manage having less energy at certain times of the day.

*I didn’t used to pay much attention to the Parkinson's on a day-to-day basis. Although I’m having to now, so I have a more ordered life. I take my meds exactly on time.*

(P3:4)
One participant carefully ordered her day and week. This was done so she could manage the things she wanted to achieve while managing her fatigue. By the end of a certain day in her week she explained:

*I'm just shattered, and you can see it. I'm shattered, I'm sweating and I'm just like... I have just about had it, you know?* (P4:10)

People with PD often discuss having decreased energy or a concern that their symptoms will interfere with their days. Having a routine meant they could achieve the things that were important to them and manage their symptoms.

**Making adaptions and using strategies**

While participants created routines so that their daily lives were easier, they also had to learn ways to manage their changing health and symptomology. Adaptions and new ways of doing things ensured participants were able to have some control over their lives and continue to work. So, while symptoms may be worsening, they were able to still feel they could do something to help themselves. Examples of this could be seen in their increase in exercise and changes to nutrition. For several participants these adaptions seemed like a project: how can I make my life simpler now? What needs to be done? What would make working easier? These were things participants could do. One participant spoke of changing her work clothes for ease of dressing. For example she no longer wore stockings and her tops were able to be pulled over her head and required no buttoning. Another participant had started using a stand-up desk at work as sitting for long periods gave her cramp and two participants had changed the way they did things to at work avoid dropping objects.

*I think you just have to adapt. At the end of the day, it is around, it is just there, and you have just got to adapt to do things differently sometimes. Reinvent. You don’t reinvent the wheel, but just reinvent your own body.* (P1:24)

Participants had also taken up exercise. For some this was new, but for others a continuation of what they had done prior to their diagnosis. Again, participants wanted to do as much as they could so they were able to continue to live what they saw as their normal life. Exercise, although difficult at times, meant they had more energy for their lives, including work.

*The lifting weights and stuff, the muscle strengthening stuff, has positive longer-term benefits for Parkinson's, so as far as I’m concerned, I do it. If I was diabetic, I’d take insulin or whatever. So, same thing. I have to do this, like it or not. It’s just something*
I have to do and that I want to do because I want to have as good life as I possibly can. (P2: 6)

All spoke of making changes to nutrition as well. Some were small changes, such as drinking more water or avoiding foods that were difficult to eat, and for others there was a conscious effort to eat in a way they saw as supporting their bodies.

I’m trying to be more careful with my nutrition. I have not come across anything about nutrition and Parkinson's, but I figure it doesn’t hurt to be sensible and healthy. (P2:9)

Self-management strategies helped participants maintain control over certain aspects of their lives. It also meant they felt they were doing something, so that while the PD may be getting worse, they were able to manage other parts of their lives. As well as this self-management strategies helped them be as healthy as they could and this meant they could continue to work.

Managing symptoms
Working with a long-term condition involved careful planning. Participants had a range of symptoms, expressing the variance and degree to which PD affected each person. Several participants explained that their symptoms were worsening, and each had made adjustments to their days in order to manage them.

It’s been two years this coming May, but I have now increased [Sinemet™] to four half tablets a day because I was finding... it would start again before I go to bed. (P4:2)

The most common symptom the participants had was fatigue and fatigue played a large part on how the participants of this study went about their lives. In the context of their work and life it played a role in decreasing the participant’s feelings of having control over their bodies, and indeed several participants expressed a feeling that fatigue controlled them.

Really, really tired, that is the worst thing. Like, go outside to, walk down there and weed the garden and walk back up again and I’m stuffed. It’s just ridiculous and it really annoys me. (P4:4)

All had made changes to the structure of their days in order to manage fatigue. It impacted on their ability to work, socialise and engage in daily activities.
I can’t muck around, I’ve got to be prepared. There is only a finite amount of energy, and I’ve to prepare it and do it. (P3:9)

For participants, days were now structured around their symptoms, especially fatigue. Again, adaptations were made to ensure their symptoms did not impact too much on what they wanted to do; work.

**Theme 3: Bridging past and future**

Participants in this study were aged between 59 and 68 years, and transitioning into older age. At the same time they also had a long-term condition. All participants expressed thoughts about looking back, on the lives they had lived. The experiences they had as their bodies began changing were exacerbated by the symptoms they had with PD: they expressed being unsure whether their symptoms were because of ageing or because of their PD. This emphasised their loss of control over their bodies. Participants often expressed fear over what was to come, emphasising their loss of control over their future.

**Feeling the loss of old lives and future lives they expected**

As participants entered another phase in their lives, they reflected back on what once was. One participant used the analogy of a hare and a rabbit. He used to be a rabbit, now he is a hare. Soon he would be a bear and hibernate. For now the younger ones at work looked after him, making sure he did not do any of the dangerous parts of his job. He now passes on knowledge.

*So, even [employee] at work, will tend to say, “I'll do that. Leave it to me.” I look back on my younger days when I would have had an older guy working for me and I would have said, “[employer], leave it I'll do it. Better off for me to do it. You stay here, I'll go up there.”* (P1:2)

PD intensified this transition, as it made them less physically able to do what was once easy.

*I know it’s creeping up on me. It’s quite hard. Once upon a time, I could walk on a scaffolding very easily. No way today. I want something to stabilise my hand... It doesn’t have to be a grip; if I can just put my fingers on it. It balances enough. I just feel a bit of a sway.* (P1:1)

For some there was sense of grief, of what they thought their lives were going to be like and adjustments had to be made to plans regarding their work.
I think I’ll probably have to sell my [business]. I have an offer on my [business]. I don’t really like that idea, but I have to sell in good time. I don’t want to become incompetent... ...It’s not what I’d have chosen to do. But I know it’s the right thing to do. I would have liked to have worked a little longer. (P3:12)

Fearing what may be to come
All participants spoke of worrying about their symptoms worsening and what was to come. PD can develop slowly, or quickly, and there is a sense of an uncertain future because of this.

I was at a conference last week and a colleague was there and he was diagnosed with Parkinson's seven or eight years ago. I hadn’t seen him for several months and he was in a wheelchair. He was able to walk but he had deteriorated so much, and that was quite scary, I thought, “Oh, it could be me in a few years.” I hope it’s not, but that uncertainty about Parkinson's is a bit... It’s not a constant, but every now and then something like that happens and I’m reminded that. (P2:7)

Most participants did not attend support groups. They did not want to see what may happen to them.

The problem with Parkinson's disease is everybody gets worse. So it’s not very uplifting. Even if I went to Alcoholic Anonymous, some of them would get better. That’s the problem, nobody gets better. (P3:17)

People with PD face an uncertain future, for some the symptoms worsen quickly and for others it can take several years before they begin to show. Participants expressed that this increased their fear of what lies in front of them and most did not go to support groups as they did not want to see what may be to come. The focus was on the now, on living the best lives they could and continuing to enjoy the things important to them, including work.

Ageing with a long-term condition
The process of ageing had begun affecting participants, but several expressed uncertainty about what was due to ageing and what was due to the PD. Also of concern was what this could mean for work. As a participant expressed, symptoms affected her ability to clearly articulate words, but there she was unsure if this was aging or a symptom of her PD.

It is probably because I am a bit slower at doing things and I am not taking it into account enough. I have always been energetic and fast at doing things. That is probably harder to come to terms with, to think about... ...It affects me a wee bit. I
sometimes have to stop and think about words, but I do not know whether that is Parkinson's or not. It could be just age related. (P5:17)

There was a sense of unfairness over getting PD that ageing was bad enough, but they then also had to deal with another set of symptoms as well.

*I think it never occurred to me... I mean, I thought it was enough having arthritis in my joints, it never occurred to me that I might get something that was chronic, and potentially disabling and incurable, you know? I suppose, like most people, I did not really think...* (P2:11)

Ageing while participants had PD often meant symptoms could be confused. This confusion added to the feelings of insecurity in their bodies as well insecurity over how long they would be able to continue to work.

**Discussion**

This study focused on staying in the workforce after a diagnosis of PD. It highlighted the different experiences of each individual and drew together common themes. Findings showed that participants sought ways to continue to work, as it was important to them and they felt they still had something to offer. Participants made adaptations in their lives so that they could remain working. Adaptations included adjusting working hours so that they could manage symptoms, trying new exercise and nutrition plans to help themselves and also creating routine in their days that best suited what they wanted to achieve.

These activities are often referred to as self-management strategies in that they improve a person’s QoL. It is argued that good self-management strategies help reduce depression and improve feelings of well-being. Tickle-Degnen et al. used a quantitative methodology, in this case questionnaires, to ascertain the benefits of teaching self-management strategies to 117 participants with PD. The authors found that using a team of physical, occupational and speech therapists to teach participant’s self-management strategies, such as benefits of exercise, coping with symptoms and aid in activities such as dressing, markedly improved QoL for their participants. Self-management strategies may also help people feel they are able to live their lives more successfully in that they help people maintain their usual life and physical abilities, two aspects seen by people with PD as living successfully.

The findings of this study are consistent with those of other qualitative research into the importance of work. Musick and Wilson argue that those who participate in work,
either volunteering or paid, are less likely to get depression. While none of the participants in this study spoke of being depressed, future research could look at the impact of work on depression for people with PD in New Zealand. Authors have also shown that working while having PD improves QoL as it helps people with PD feel more in control of their lives and their bodies (11,12,28). In the study reported here participants spoke of enjoying their work and still feeling they had something to offer. Future research could ascertain to what degree the improvement occurs.

Visibility of symptoms was found to be a limiting factor to work participation (13) in research into working after a diagnosis of PD. Tremor, difficulty walking, falling or freezing all inhibited full participation in work but it was especially the severity of symptoms, when they were present, that inhibited people the most. In contrast, the participants in the current study did not discuss problems with symptoms, apart from fatigue, as limiting their work participation, findings which were more in-line with participants in a study undertaken by Kang and Ellis-Hill (12). These authors reported that it was the participants’ ability to live as normal life a possible that determined how successful they judged their lives. They suggest healthcare providers determine what constitutes a normal life for people with PD and support them to enable this to continue for as long as possible.

More worrisome than visible symptoms for participants in this study was fatigue as it emphasised their loss of trust in their body. Fatigue was a symptom that needed careful management and planning so that participants could do the most with their days. This is consistent with a study that reported that where participants were having to make constant adjustments to their lives, their bodies were now seen as a burden and they lost a sense of security of what it was capable of doing (21).

Having PD also emphasised participants’ grief as they faced an uncertain future. This was exacerbated by their ageing. Participants’ spoke of being unsure what was due to their condition and what was due to ageing. However, unlike the Roy and Giddings (32) research, participants here did not describe ageing as overshadowing their experiences with PD. Instead, they found it difficult to differentiate between their PD symptoms and those of ageing.

The experience of keeping working to keep working meant participants made adaptations and using strategies so that they could continue doing something important to them. Future research could explore at greater depth other elements brought up in the study. Although
participants did not specifically address these, there were subtexts to the findings. For example; perhaps one of the motivations to continue to work was to ensure PD was not overcoming them and that participants were not being overwhelmed by the condition. Another could be that perhaps by working the participants did not feel a burden to those around them. These are worthy of deeper research in the future.

**Limitations of the study**

The small number of participants in the research reported here limits the general applicability of findings to a wider group of people who experience the phenomenon. Thorne (26) argues, however, that a small number is appropriate in an under-researched field. In a larger study the researcher’s growing knowledge of the topic may lead to deeper exploration as the interviewing proceeds, and this was naturally missing in a study of this size.

**Conclusion**

Continuing to work after a diagnosis of PD is an under-researched field and this study aimed to address this by interviewing five people who experience the phenomenon. The findings of the study show that work remained an important part of the participant’s lives as they still felt they had something to offer and they enjoyed working. In order for work to continue, however, participants had to constantly learn ways to manage PD. They created routine, used self-management strategies and managed their symptoms. At the same time they also faced an uncertain future. Participants reflected back on the lives they once lived as they transitioned into another phase of their lives. Work was a way this could be articulated as they reflected on their changing roles in the work space or they expressed grief over the future lives they expected. Workplaces also needed to be supportive, by accommodating different work hours or office set-ups. Participants spoke with positivity about their workplaces when they felt supported and understood.

For healthcare providers the ability to listen and hear, and then collaborate with people with PD is important. Plans could be made that are individual as well as flexible so that people with PD can continue undertaking activities important to them. Findings ways to live successfully with PD is an ongoing process, one that requires keeping working to keep working.
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Appendix 1: Author guidelines for Scandinavian Journal of Caring Sciences

Online publication from 2016

The Scandinavian Journal of Caring Sciences will be published in online-only format effective with the 2016 volume. This is a proactive move towards reducing the environmental impact caused by the production and distribution of printed journal copies and will allow the journal to invest in further digital development. Published articles will continue to be disseminated quickly through the journal’s broad network of indexing services, including ISI, MEDLINE and Scopus. Articles will also continue to be discoverable through popular search engines such as Google. All colour images will now be reproduced digitally and published free of charge.

Aims and Scope

The Scandinavian Journal of Caring Sciences is an established quarterly, peer reviewed Journal with an outstanding international reputation. As the official publication of the Nordic College of Caring Science, the Journal shares their mission to contribute to the development and advancement of scientific knowledge on caring related to health, well-being, illness and the alleviation of human suffering. The emphasis is on research that has a patient, family and community focus and which promotes an interdisciplinary team approach. Of special interest are scholarly articles addressing and initiating dialogue on theoretical, empirical and methodological concerns related to critical issues. All articles are expected to demonstrate respect for human dignity and accountability to society. In addition to original research the Journal also publishes reviews, meta-syntheses and meta-analyses. Papers are expected to have a focus on those receiving care, and have a sound scientific, theoretical or philosophical base. Ethical considerations must be discussed as appropriate.

Papers exceeding 5000 words will not usually be accepted. This 5000 word count includes the abstract, text, author contributions, ethical approval and funding, but not figures or tables and references. It is not journal policy to publish papers submitted in two parts. All manuscripts are double-blind refereed. Review papers should include the words ‘review’ or ‘literature review’ in the title.

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Appendix 2: Advertisement for Parkinson’s New Zealand newsletter

‘Living and working with Parkinson's disease in New Zealand’

A new study is being undertaken in Auckland that needs participants. The aim of this study is to explore the experience of living with Parkinson’s disease in New Zealand. Of particular interest is the experience of living day-to-day in regards to work, recreation and your continued healthcare within a New Zealand context. It is hoped that in response to the study a practitioner may improve their care for people with Parkinson’s disease. The researcher is a Masters Osteopath student. Osteopaths consider health to be a combination of many factors: physical, mental, emotional and spiritual. In order to help people with a physical illness osteopaths develop an awareness of these other domains in a bid to offer better treatment. It is having a better sense of these other domains in people with Parkinson’s disease that will be explored in the study.

In order to explore the lived experience of people with Parkinson’s disease the researcher needs to interview four to five participants who are willing to be interviewed once or twice about having Parkinson’s disease. These participants need to be working at least 24 hours a week as the study is interested in people still working.

If participating in this study interests you, and you fulfil the inclusion criteria, please either email the researcher, Elissa Brittenden, on Parkinsontestudynewzealand@gmail.com or ring her on: 021 441 323
Appendix 3: Participant information sheet

Information for participants

Research Project Title:

Living and working with Parkinson's disease in New Zealand

Synopsis of project:

The aim of this study is to explore the experience of people in New Zealand who have Parkinson’s disease. It will take a wide, open view and allow participants to share what is important to them. However, participants must be working at least 24 hours of each week. The focus of questioning will be on a participant’s life with Parkinson’s disease while they work as well as how they interact with New Zealand health services.

What we are doing:

In this study the researcher, Elissa Brittenden, will be interviewing participants. Each interview will take approximately one hour each.

What it will mean for you:

The study will involve you, as a participant, being interviewed once or twice. The number of interviews will be dependent on how much we are able to cover during the first interview. The interview will be conducted at Clinic 41, at Unitec’s Mt Albert campus, at your own home or a place most convenient to you. Interviews will be audio-recorded and later transcribed (put into written format – transcript)

If you agree to participate, you will be asked to sign a consent form. This does not stop you from changing your mind if you wish to withdraw from the project. But, if you choose to withdraw it must be done within two weeks of having your interview.

Your name and any information that may identify you will be kept completely confidential. All information collected from you will be stored on a password protected file and only myself and my supervisors will have access to this information.

Please contact me if you need more information about the project. My email address is: Parkinsonsstudynewzealand@gmail.com and contact phone number is 021 441323
At any time if you have any concerns about the research project you can contact my supervisor: My supervisor is Associate Professor Dianne Roy, phone 815-4321 ext. 8307, mobile number: 021 581096 or email droy@unitec.ac.nz

UREC REGISTRATION NUMBER: 2015-1055

This study has been approved by the UNITEC Research Ethics Committee from 9<sup>th</sup> September 2015 to 9<sup>th</sup> September 2016. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary (ph: 09 815-4321 ext 8551). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
Appendix 4: Interview questions

Short introduction:
Below are bullet points outlining the topics that each interview will cover. The aim of each interview is to be semi-structured, open and that information comes from the participant rather than specifically driven by myself. Prior to starting an interview a consent form will be signed by each participant. On completion of the interviews the participants will be offered a copy of the transcription if they would like one.

Each interview will begin with a standard opening; it will outline content and conditions of withdrawal. This opening will also ascertain if there are any specific needs for the participant such as allowing for slow speech patterns. It will also ensure each participant agrees to be recorded. Each interview will also close with an invitation to add anything not yet covered, reiterate the withdrawal conditions and discuss the sending of the transcribed interviews as well as any information or notification of completion or publication the participant would like to have.

Bullet point potential topics:

First interview: focus on life history, diagnosis
- Tell me about your life leading up to diagnosis
- What has been your experience with Parkinson’s disease once you were diagnosed?

Second interview: focus on healthcare, day-to-day life
- Tell me about your day-to-day life
- How do you find working with Parkinson’s disease?
- Does the medication help or hinder your ability to work?
- If you have work colleagues, have you disclosed your condition and how was the response from them
- What has been your experience of the health care system?
- How could health care providers improve their care?
Appendix 5: Transcriptionist confidentiality form

Research Title: Living and working with Parkinson's disease in New Zealand

Researcher/s Name: Elissa Brittenden

Address: 2/329 Point Chevalier Road, Point Chevalier, Auckland

Phone number: 021441323

Email: kongirlnz@gmail.com

I ___________ (full name - please print)

Agree to treat in absolute confidence all information that I become aware of in the course of transcribing the interviews or other material connected with the above research topic. I agree to respect the privacy of the individuals mentioned in the interviews that I am transcribing. I will not pass on in any form information regarding those interviews to any person or institution. On completion of transcription I will not retain or copy any information involving the above project.

I am aware that I can be held legally liable for any breach of this confidentiality agreement, and for any harm incurred by individuals if we disclose identifiable information contained in the audiotapes and/or files to which we will have access.

Signature: ____________________________ Date: ____________________________

UREC REGISTRATION NUMBER: ####

This study has been approved by the UNITEC Research Ethics Committee from (date) to (date). If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary (ph: 09 815-4321 ext 8551). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
Appendix 6: Extended findings section
Mind-maps: Individual participants
Appendix 7: Extended findings section
Mind-maps: Themes from across data

[Diagram of mind-maps with themes such as fatigue, being grateful, aging, adaptation, exercise/nutrition, managing symptoms, and more.]

1. Adaptations
   - Exercise/Nutrition
   - Managing symptoms
   - Fatigue

2. Loss of old life
   - Aging
   - Being grateful
   - Shame/Vulnerability
   - Healthcare
   - Not wanting to be seen as sick

3. Not being seen as sick
   - Shame
   - Interactions with healthcare providers
   - Other aches/pains
   - Are they PJs? Unmillion?
Appendix 8: Ethics approval

Elissa Brittenden
2/329 Point Chevalier Road
Point Chevalier
Auckland 1022

24.9.15

Dear Elissa,

Your file number for this application: 2015-105S
Title: Living and working with Parkinson's disease in New Zealand.

Your application for ethics approval has been reviewed by the Unitec Research Ethics Committee (UREC) and has been approved for the following period:

Start date: 9.9.15
Finish date: 9.5.16

Please note that:
1. The above dates must be referred to on the information AND consent forms given to all participants.
2. You must inform UREC, in advance, of any ethically-relevant deviation in the project. This may require additional approval.

You may now commence your research according to the protocols approved by UREC.

We wish you every success with your project.

Yours sincerely,

[Signature]

Sara Donaghey
Deputy Chair, UREC

cc: Elizabeth Niven
Cynthia Almeida
Appendix 9: Extended findings section

Theme development

First: Theme 3: Aging? Bridging past and future?

Subtheme: Loss of old lives and future lives they thought they would have

Participant one: rabbit/hare analogy

“So, even [employee] at work, one of my [employee], will tend to say, "I'll do that. Leave it to me." And I look back on my younger days when I've had an older guy working for me and I'd said, "[employer], leave it I'll do it. Better off for me to do it. You stay here, I'll go up there."(P1, pg. 2)

Grief:

“I think I probably have to sell my [business]. I've got an offer on my [business]. I don't really like that idea, but I have to sell in good time. I don't want to become incompetent.”

Interviewer: How's that for you?

“It's not what I would have chosen to do. But I know it's the right thing to do. But I would have like to have worked a little longer. The other thing that I won't get to do, is they're putting in a 30 chair annex of the [medical school]. And I would have like to have been a teacher there, to get to do that. So, yeah, there are some things. But I sort of look at it, "Well, you could have a stroke tomorrow and you won't get to do it either." So that's the major changes in my life. And people say, "Oh what are you gonna do when you retire?" And I think, "Get dressed, get out of bed."(P3, Pg. 12)

Subtheme: Fear of what is to come

“Which surprised me because, most people refer to as Parkinson's, are in their 70s or late 60s. One of the other guys I knew that passed away, he was in his mid-60s. But he
was pretty bad. He couldn't get out of the vehicle in the morning. He'd turn up for work and he'd struggle to get out of the vehicle, you know, he'd struggle.” (P1, Pg. 5)

“I was at a conference last week and a colleague was there and he was diagnosed... He's a little big younger than me, and he would have been diagnosed with Parkinson's seven or eight years ago, I think. And I hadn't seen him for several months and he was in a wheelchair. He was able to walk but he'd deteriorated so much, and that was quite scary, I thought, “Oh, it could be me in a few years.” I hope it's not, but that uncertainty about Parkinson's is a bit... It's not a constant, but every now and then something like that happens and I'm reminded that.” (P2, Pg. 7)

“The problem with Parkinson's disease is everybody gets worse. So it's not very uplifting. Even if I went to Alcoholic Anonymous, some of them will get better. And that's the problem, nobody gets better and that.” (P3, Pg. 17)

“Yeah, it's just that my legs are getting so stiff now that, you know, you got to wonder how much can you, how much longer can you keep going” (P4, Pg. 6)

“I do go to a Parkinson's coffee group through the Parkinson's Society. There's been nobody joined since I joined, the one I go to. So, I just see all these other ones getting worse, and nobody coming in that's at my level. I'm the only one that works. I go because I think it's nice to hear things maybe that I will experience at some stage, or how people are dealing with it. Sometimes I think, “Oh gosh, it's a bit depressing.” But I still go.” (P5, Pg. 9)

Subtheme: Aging with a LTC

“It seems to make me slow down. Cleaning the car has gotten a lot more difficult. Used to be quite easy to flick around the cars and wash them down, but not now it's a
bit slower. But I still put some of that down to age. You know? So, it's one of those things.” (P1, Pg. 6)

“It's amazing how you compare yourself. A 21 year old young fellow's a rabbit, and then you move down to the rabbit/hare situation type of thing, and then to the tortoise. Then you go into a bear and hibernate.” (P1, Pg. 15)

“I think it had never occurred to me... I mean, I thought it was enough having arthritis in my joints, it never occurred to me that I might get something that was chronic, and potentially disabling and incurable, you know? I suppose, like most people, don't really think... ” (P2, Pg. 11)

“It's probably because I'm a bit slower at doing things and I'm not taking it into account enough. I've always been energetic and fast at doing things. That's probably harder to come to terms with, to think about. Sometimes I even find it hard and probably I'm not as... I can't think of the word. I was going to say eloquent, but it's not quite the word. I know what I want to say, but I can't explain it as well as I would have in the past. I find that at sometimes at work, too. It affects me a wee bit. I sometimes have to stop and think about words, but I don't know whether that's Parkinson's or not. It could be just age related. Yes, I'm not as clear and concise in my verbal conversations as I would have been in the past, I think.” (P5, Pg. 17)
Second: Theme 3: Bridging past and future

Participants in this study were aged between 59 and 68, and transitioning into older age. At the same time they also had a long-term condition. All participants expressed words about looking back, on the lives they had lived. The experiences they had as their bodies began changing were exacerbated by the symptoms they had with PD, they expressed being unsure if their symptoms were because of aging or because of their PD. This emphasised their loss of control over their bodies because they were unsure what was what. Furthermore, they expressed fear over what was to come. Again, emphasising their loss of control.

Loss of old lives and future lives they thought they would have

As participants entered another phase in their lives, they reflected back on what once was. One participant used the analogy of a hare and a rabbit. He used to be a rabbit, now he is a hare. The younger ones at work are looking after him, making sure he doesn’t do any of the dangerous parts of his job. He now passes on knowledge.

So, even [employee] at work, one of my employees, will tend to say, "I'll do that. Leave it to me." And I look back on my younger days when I would have had an older guy working for me and I would have said, "[employer], leave it I'll do it. Better off for me to do it. You stay here, I'll go up there." (P1:2)

PD intensified this transition, as it made them less physically able to do what was once easy.

I do tend to have a sit down every now and then. I never used to but I am not getting any younger either, so... But some of it I feel is age, and I've been in the [manual labour] 35 years. So, it just seems to come with the work, with the job, too, I feel. I know it's creeping up on me. It is quite hard. Once upon a time, I could walk on a [high frame] very easily. No way today. I want something to stabilise my hand... It does not have to be a grip; I can just put my fingers on it. It balances enough. Just feel a bit of a sway. (P1:1)

For some there was sense of grief, of what they thought their lives were going to be like. Adjustments had to be made to plans.

I think I will probably have to sell my [business]. I have an offer on my [business]. I do not really like that idea, but I have to sell in good time. I do not want to become incompetent.
Interviewer: How is that for you?

*It is not what I would have chosen to do. But I know it is the right thing to do. But I would have liked to have worked a little longer.* (P3:12)

One participant spent time talking about events that had occurred in his life, reflecting on the things he had done and then said:

*So you do those things in the Book of Life. And then you get a good old kick in the ass and you bloody slow up a bit.* (P1:20)

**Fear of what is to come**

All participants spoke of worrying about their symptoms worsening and what was to come. PD can develop slowly, or quickly, and there is a sense of an uncertain future because of this.

*I was at a conference last week and a colleague was there and he was diagnosed with Parkinson's seven or eight years ago. I hadn't seen him for several months and he was in a wheelchair. He was able to walk but he'd deteriorated so much, and that was quite scary, I thought, "Oh, it could be me in a few years." I hope it's not, but that uncertainty about Parkinson's is a bit... It's not a constant, but every now and then something like that happens and I'm reminded that.* (P2:7)

Most participants did not attend support groups. They did not want to see what may happen to them.

*The problem with Parkinson's disease is everybody gets worse. So it is not very uplifting. Even if I went to Alcoholic Anonymous, some of them will get better. That is the problem, nobody gets better.* (P3:17)

*I do go to a Parkinson's coffee group through the Parkinson's Society. There has been nobody joined since I joined, the one I go to. So, I just see all these other ones getting worse, and nobody coming in that's at my level. I am the only one that works. I go because I think it's nice to hear things maybe that I will experience at some stage, or how people are dealing with it. Sometimes I think, "Oh gosh, it's a bit depressing." But I still go.* (P5:9)
In order to overcome this, several participants spoke of focusing on living for the here and now.

*Because there is no point in worrying about a future that may or may not eventuate, when I can plan for a good future, I do not mean being totally careless, but there is no point in me living anxiously.* (P2:4)

**Aging with a long-term condition**

The process of aging had begun slowing down participants, but several expressed uncertainty about what was aging and what was due to the PD.

*It is probably because I am a bit slower at doing things and I am not taking it into account enough. I have always been energetic and fast at doing things. That is probably harder to come to terms with, to think about... ...It affects me a wee bit. I sometimes have to stop and think about words, but I do not know whether that is Parkinson's or not. It could be just age related.* (P5:17)

There was a sense of unfairness over getting PD, that aging was bad enough but they also had to deal with another set of symptoms as well.

*I think it had never occurred to me... I mean, I thought it was enough having arthritis in my joints, it never occurred to me that I might get something that was chronic, and potentially disabling and incurable, you know? I suppose, like most people, did not really think...* (P2:11)

**Third: Near complete**

**Theme 3: Bridging past and future**

Participants in this study were aged between 59 and 68, and transitioning into older age. At the same time they also had a long-term condition. All participants expressed words about looking back, on the lives they had lived. The experiences they had as their bodies began changing were exacerbated by the symptoms they had with PD: they expressed being unsure whether their symptoms were because of aging or because of their PD. This emphasised their
loss of control over their bodies. Participants often expressed fear over what was to come, emphasising their loss of control over their future.

**Loss of old lives and future lives they expected**

As participants entered another phase in their lives, they reflected back on what once was. One participant used the analogy of a hare and a rabbit. He used to be a rabbit, now he is a hare. Soon he would be a bear and hibernate. For now the younger ones at work looked after him, making sure he did not do any of the dangerous parts of his job. He now passes on knowledge.

> So, even [employee] at work, will tend to say, "I'll do that. Leave it to me." I look back on my younger days when I would have had an older guy working for me and I would have said, "[employer], leave it I'll do it. Better off for me to do it. You stay here, I'll go up there." (P1:2)

PD intensified this transition, as it made them less physically able to do what was once easy.

> I know it is creeping up on me. It is quite hard. Once upon a time, I could walk on a scaffolding very easily. No way today. I want something to stabilise my hand... It does not have to be a grip; if I can just put my fingers on it. It balances enough. I just feel a bit of a sway. (P1:1)

For some there was sense of grief, of what they thought their lives were going to be like and adjustments had to be made to plans.

> I think I will probably have to sell my [business]. I have an offer on my [business]. I do not really like that idea, but I have to sell in good time. I do not want to become incompetent... ...It is not what I would have chosen to do. But I know it is the right thing to do. I would have liked to have worked a little longer. P3:12)

One participant spent time talking about events that had occurred in his life, reflecting on the things he had done and then said:

> So you do those things in the Book of Life. And then you get a good old kick in the ass and you bloody slow up a bit. (P1:20)

**Fear of what is to come**

All participants spoke of worrying about their symptoms worsening and what was to come. PD can develop slowly, or quickly, and there is a sense of an uncertain future because of this.
I was at a conference last week and a colleague was there and he was diagnosed with Parkinson’s seven or eight years ago. I had not seen him for several months and he was in a wheelchair. He was able to walk but he had deteriorated so much, and that was quite scary, I thought, “Oh, it could be me in a few years.” I hope it is not, but that uncertainty about Parkinson’s is a bit... It is not a constant, but every now and then something like that happens and I am reminded that. (P2:7)

Most participants did not attend support groups. They did not want to see what may happen to them.

_The problem with Parkinson's disease is everybody gets worse. So it is not very uplifting. Even if I went to Alcoholic Anonymous, some of them would get better. That is the problem, nobody gets better._ (P3:17)

People with PD face an uncertain future, for some the symptoms worsen quickly and for others it can take several years before they begin to show. For participants this increased their fear of what lies in front of them and most did not go to support groups as they did not want to see what may happen to them.

**Aging with a long-term condition**

The process of aging had begun effecting participants, but several expressed uncertainty about what was aging and what was due to the PD.

_It is probably because I am a bit slower at doing things and I am not taking it into account enough. I have always been energetic and fast at doing things. That is probably harder to come to terms with, to think about... ...It affects me a wee bit. I sometimes have to stop and think about words, but I do not know whether that is Parkinson's or not. It could be just age related._ (P5:17)

There was a sense of unfairness over getting PD that aging was bad enough, but they also had to deal with another set of symptoms as well.

_I think it had never occurred to me... I mean, I thought it was enough having arthritis in my joints, it never occurred to me that I might get something that was chronic, and potentially disabling and incurable, you know? I suppose, like most people, I did not really think..._ (P2:11)

Aging while participants had PD often meant symptoms could be confused. This confusion added to the feelings of insecurity in their bodies.
Appendix 10: Participant consent form

Participant Consent Form

Research Project Title: Living and working with Parkinson's disease in New Zealand

I have had the research project explained to me and I have read and understand the information sheet given to me.

I understand that I don't have to be part of this research project, should I chose not to participate, and I may withdraw at any time up until two weeks after having my interview.

I understand that everything I say is confidential and none of the information I give will identify me and that the only persons who will know what I have said will be the researcher and her supervisors. I also understand that all the information that I give will be stored securely at Unitec for a period of 5 years.

I give permission for my discussion with the researcher to be audio recorded and transcribed.

I understand that I can see the finished research document, should I request it.

I have had time to consider everything and I give my consent to be a part of this project.

Participant Name: …………………………………………………………………………………….

Participant Signature: …………………….. Date: ……………………..

Project Researcher: ……………………………….. Date: ………………………………..

UREC REGISTRATION NUMBER: 2015-1055

This study has been approved by the UNITEC Research Ethics Committee from 9th September 2015 to 9th September 2016. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary (ph: 09 815-4321 ext 8551). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
Declaration:

Name of candidate: Elissa Brittenden

This thesis entitled Keeping working to keep working: Staying in the workforce with a diagnosis of Parkinson’s disease is submitted in partial fulfilment for the requirements for the Unitec degree of Master of Osteopathy.

Candidate’s declaration

I confirm that:

- This thesis represents my own work.
- Research for this work has been conducted in accordance with the Unitec Research Ethics Committee Policy and Procedures, and has fulfilled any requirements set for this project by the Unitec Research Ethics Committee.
- Ethics Approved by the Unitec Research Ethics Committee Policy and Procedures (2015-1055)

Candidate Signature: Elissa Brittenden      Date: 19th September, 2016

Student number: 1401682
Full name of author: Elissa Joy Bittenden

Full title of thesis/dissertation/research project ("the work"): Keeping on working to keep working: Staying in the workforce with a diagnosis of Parkinson's disease

Practice Pathway: Health Care

Degree: .

Year of presentation: 2016

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Date: 21/09/2016