

# **Exploring the work experiences of people with multiple sclerosis**

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## **Abstract**

### **Background:**

The large variety of multiple sclerosis (MS) symptoms and its unpredictable disease course contributes to it having a negative impact in every area of life, with employment issues being of significant concern for people with MS. Unemployment rates are very high in people with MS, and are associated with a reduced quality of life and increased financial burden for the individuals with MS as well as the wider society. The literature indicates that people with MS usually leave work of their own choosing and often before the disease has rendered them incapable of working. The relationship between disease-specific, demographic, and contextual factors and employment issues is complex and requires further investigation.

### **Aim:**

To explore and create a better understanding of the work experiences of people with MS.

### **Methods:**

Semi-structured interviews were completed with nine people (six women and three men) with MS, who were working. These interviews were recorded, transcribed and subject to interpretative phenomenological analysis (IPA).

### **Results:**

All of the participants had tertiary level education. It was clear from the participants' interviews that maintaining employment was challenging and their stories illustrated that work changes were inevitable. Despite distinctly different employment experiences, there were many common themes that linked the participants' experiences together. The first theme of '*Challenge*' ran throughout the narrative and was related to the MS diagnosis, its unpredictable progressive disease course, and the acceptance of it and the subsequent work changes required. A second theme was '*Choice and control*' where the participants took control of their MS, and lives by being actively involved in choosing the work changes needed. The '*Preparation for change*' theme illustrated the catalysts and influences leading to work changes, while the '*Consequence of change*' theme explored not only the benefits of change, but also the demands imposed on the participants and others because of the work changes.

**Discussion and conclusion:**

The finding of this study supports previous literature that employment issues for people with MS are complex. It is however, one of the first studies that revealed the complexities associated with making work changes that enable people with MS to continue working. It would benefit people with MS if they were more cognisant of their changing capacity for work due to their evolving MS symptoms, in particular fatigue, physical problems and cognitive changes, and themselves instigated the necessary changes to be made for them to continue at work. In order to make successful changes, people with MS need to find acceptance of their condition, and possibly change their outlook on their future lives. It might be prudent to offer vocational support services to help them manage the challenges of working while living with MS and to help facilitate work changes. Clinicians could address issues around acceptance and disclosure, and promote and facilitate clients to maintain control of their choices. Further research is required to explore the experiences of those who have stopped work and those in manual labour type roles, and also what support services would provide the most effective support for people with MS.

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It has been a challenging journey over the last two years, but on completion of this thesis I feel strengthened with knowledge and proud of my achievement. I would not have got to this point without the help and support of a great number of people.

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## **List of abbreviations**

MS - Multiple sclerosis

IPA - Interpretative phenomenological analysis

CI – Confidence interval

EDSS - Expanded Disability Severity Scale

HRQOL - Health-related quality of life

## **Chapter 1 Introduction**

### **1.1 Study background**

Through my clinical role I have met a large number of young adults with multiple sclerosis (MS) who were either struggling to work or had already given up work because of issues related to their MS. As part of my postgraduate diploma in rehabilitation I began to explore the existing published literature that investigated issues in relation to MS and employment. It quickly became apparent that unemployment rates are high among people with MS, with them often stopping work soon after diagnosis, even when their impairments are still at a relatively low level. It was also obvious that multiple factors, including disease characteristics, as well as environmental and social factors may contribute to the difficulties people with MS experience at work.

This motivated me to explore this topic further; hence completing a research based thesis for my Masters in Health Science. The aim of this study therefore was to explore the work experiences of people with MS.

### **1.2 Researcher's background**

I have worked for the past six years as a physiotherapist at 'Multiple Sclerosis and Parkinson's Canterbury' in Christchurch, New Zealand. Through delivery of services to individuals with MS, I have become aware of the multiple issues and concerns that they have around work and employment, and the complex interactions contributing to this problem. Given that many of my clients are young adults and in the early years of their careers, issues with employment are often one of their major concerns. If I am to better support my clients in this regard, I needed to become more familiar with how issues arise, and what could be helpful in addressing them.

### **1.3 Research aim**

My experience as a clinician working with people with MS, along with the existing literature, identified a need to explore the complexity of issues people with MS experience when working. This created the aim of this thesis: to explore and create a better understanding of the work experiences of people with MS. The intention of this thesis was to shed light on the work experiences of people with MS and identify what helps and hinders them in working and in remaining at work after a diagnosis of MS. In combination with the existing literature, the results will help provide a better understanding of the problems faced by people with MS and help develop better interventions to allow people with MS to manage their symptoms and facilitate employment.

### **1.4 Definition of key terms**

#### **Multiple sclerosis**

Multiple sclerosis is a progressive, unpredictable, demyelinating disease of the central nervous system, affecting the brain and spinal cord (Rumrill Jr, 2009).

#### **Work/employment**

The terms work and employment have been used interchangeably in this thesis. In the context of this thesis, I have used both terms to refer to a paid occupation by which a person earns a living.

### **1.5 Thesis structure**

This thesis outlines the background to this research, the methods used to conduct the study, and the results that emerged. In chapter two, the existing literature in relation to MS and work is explored and justification for this research is presented. The third chapter provides an overview of the methodological framework of interpretative phenomenological analysis (IPA), and the methods used in this study. The results from the research are presented in chapter four. Finally the discussion

chapter reviews the current results in relation to the existing published literature, and makes recommendations for clinical practice and future research.

## **Chapter 2 Background and literature review**

### **2.1 Multiple sclerosis**

#### **Definition, incidence, prevalence and types of MS**

Multiple sclerosis (MS) is a progressive, unpredictable, demyelinating disease of the central nervous system, affecting the brain and spinal cord (Rumrill Jr, 2009). It is the most common non-traumatic neurological condition in young adults (Alonso & Hernan, 2008; Stys, Zamponi, van Minnen, & Geurts, 2012).

In America, Europe, and Australia, the average incidence of MS has been estimated to be 3.6 per 100,000 for women and 2.0 per 100,000 for men (Alonso & Hernan, 2008). There has been no study on incidence in New Zealand, but a prevalence study found that MS affects approximately 3000 people (prevalence rate of 72 per 100,000) (Taylor et al., 2009).

MS can occur at any age, but diagnosis is often made between the ages of 20 and 40 (Rumrill Jr, 2009). It is more common in women than men and the ratio of women compared to men is increasing (Alonso & Hernan, 2008). In New Zealand the ratio is three females to one male (Taylor et al., 2009). It is more common in New Zealand Europeans, with the prevalence in Maori being only 17.5 per 100,000 (Taylor et al., 2009). The prevalence of MS in New Zealand, as in other parts of the world, appears to be linked to the latitude of residence, with the prevalence in southern parts of New Zealand higher than in more northern areas of the country (Taylor et al., 2009).

There are three principal types of MS: relapsing-remitting, primary progressive and secondary progressive. Relapsing-remitting MS is the most common form of the disease with about 80% of MS cases beginning in this manner (Stys et al., 2012). A relapse occurs due to a “flare-up” of demyelination with subsequent acute decline in neurological functioning, followed by remission with partial or full recovery dependent on the level of re-myelination (Lassmann, van Horssen, &

Mahad, 2012). Two-thirds of people with relapsing-remitting MS develop secondary progressive MS, characterised by a steadier progressive decline in function with no evident periods of relapses or remissions. Ten percent of people with MS have primary progressive MS, with a slow but steady decline in function from disease onset due to ongoing demyelination and neurodegenerative changes (Lassmann et al., 2012).

### **Pathophysiology of MS**

The inflammatory disease process destroys the myelin (a fatty tissue surrounding the nerve axons) in multiple and varied locations in the brain and spinal cord (Rejdak, Jackson, & Giovannoni, 2010).

Damaged myelin compromises nerve impulse conduction, creating impairments of physical, sensory, cognitive and emotional function. The inflammatory process creates scar tissue plaques on the myelin, which further impedes nerve impulse conduction and leads to the progressive nature of MS (Lassmann et al., 2012). In the progressive forms of MS, in addition to the inflammatory disease process causing demyelination, there are also neurodegenerative changes (Lassmann et al., 2012; Stys et al., 2012).

While the aetiology of MS is currently unknown; it is believed to be an auto-immune condition with possible immunological, genetic and environmental risk factors (Rejdak et al., 2010). It has been hypothesised that MS develops when a person who is genetically susceptible encounters environmental agents such as a virus that then triggers the auto-immune response (Rumrill Jr, 2009).

### **Diagnosis of MS**

The diagnosis of MS is made by the presence of central nervous system symptoms, often confirmed with magnetic resonance imaging. There is no confirmatory diagnostic test (genetic, or immunological), so it is important to rule out other possible conditions that have a similar presentation (Rumrill Jr, 2009). Diagnosis can take some time and an individual may experience

multiple presentations before a diagnosis is confirmed. Not all reported symptoms can be directly attributed to changes on central nervous system scans, although advances in brain imaging technology have improved the speed and accuracy of diagnosis (Rumrill Jr, 2009).

### **Consequences of MS**

There is a wide variety of symptoms associated with MS, determined by the location and size of the demyelination process. This means that no two people with MS will experience the same presentation of symptoms or disease progression (Rejdak et al., 2010).

Symptoms include fatigue, mobility and balance problems, spasticity, numbness and tingling, muscle weakness, visual impairments, bowel and bladder dysfunction, and sexual dysfunction. It also impacts on an individual's psychological function with symptoms such as cognitive dysfunction, depression and anxiety (Rumrill Jr, 2009).

This broad range of physical and psychological problems has a negative impact on the personal and social functioning of people with MS and also their quality of life (Forbes, While, Mathes, & Griffiths, 2006). Given that the diagnosis is often made in young adulthood, it can have a large impact on an individual's ability to raise a family and develop a career (Rumrill Jr, 2009).

## **2.2 Employment and MS**

### **Unemployment rates**

The diagnosis of MS is typically made when adults are of working age and in the early stages of their careers (Johnson et al., 2004; Julian, Vella, Vollmer, Hadjimichael, & Mohr, 2008; Yorkston et al., 2003). In the USA only 20-40% of individuals with MS are still working 15 years after their diagnosis, despite approximately 90% of them having a history of employment and most of them working at the time of their diagnosis (Bishop et al., 2013; Roessler, Neath, McMahon, & Rumrill, 2007). A study in the United Kingdom demonstrated that 77% of people with MS had been employed at diagnosis,

but 43% had stopped work on average 11.9 years after their diagnosis (Moore et al., 2013).

Compared to Moore and colleagues study (2013), other studies from the UK, USA and Australia suggest that unemployment happens more quickly and at lower levels of disability, with between 50-80% being unemployed five years after diagnosis (Forbes et al., 2006; Green & Todd, 2008; Julian et al., 2008; Simmons, Tribe, & McDonald, 2010). Despite high unemployment rates, 80% of people with MS who have become unemployed believe they retain the ability to work and between 40% to 75% report they would like to return to work (Julian et al., 2008; O'Connor, Cano, Ramio i Torrenta, Thompson, & Playford, 2005).

Employment rates appear to differ depending on the type of MS. In one study, the general population of people with MS had an unemployment rate of 83% compared to 21% among a subset of people with MS who had a low level of disability (Glad, Nyland, Aarseth, Riise, & Myhr, 2011). Similarly, in another population of people with relapsing and remitting MS and low levels of disability, only 24% were unemployed (Glanz et al., 2012).

However, in addition to high unemployment, a higher proportion of people with MS work part-time compared to the general population (Simmons et al., 2010). For example, 55% of a group of 221 people with MS in the UK who were employed had changed their working hours (Moore et al., 2013).

The current unemployment rate for people with MS in New Zealand is thought to be approximately 54% (D. Mason, personal communication of unpublished research, November 15, 2016). This is considerably higher than the national unemployment rate of 5.8% (Statistics New Zealand, 2016).

Even in comparison to people with other neurological conditions, the rate of unemployment in people with MS appears to be high. The unemployment rate for young adults with a stroke (under 50 years) is between 26% - 44% (Maaijwee et al., 2014), for individuals with a traumatic brain injury it is 47% (Andelic, Stevens, Sigurdardottir, Arango-Lasprilla, & Roe, 2012) and for those with spinal

cord injury it is between 33-79% ,dependent on level and severity of injury (Lidal, Huynh, & Biering-Sorensen, 2007).

High unemployment in a population who should be in the prime of their careers and working life is a cause for concern. Better understanding of the reasons for this high unemployment rate would enable clinicians to better support their clients to remain in work and help identify individuals who may be at risk of losing employment.

### **Factors that contribute to employment status change**

A number of factors, including disease characteristics, environmental and social factors, may contribute to the difficulties people with MS experience at work (Simmons et al., 2010). The following is a narrative review of the literature that investigated issues with employment for people with MS. Table 2.1 gives an indication of the scope of the search strategy.

Table 2.1: Literature search strategy

<b>Databases</b>	Ovid, EBSCO, Cochrane, PEDro
<b>Key words</b>	Multiple Sclerosis, MS, Work, Employment, Job
<b>Publication years</b>	2004 – 2015. In addition, key articles published prior to 2004 that were frequently referenced by more recent publications were also reviewed.
<b>Inclusion/Exclusion criteria</b>	Studies had to include only people with MS and needed to address an issue in relation to paid work/employment.  Any type of study

Articles were reviewed for quality using the relevant Critical Appraisal Skills Programme checklist for each type of study design (Critical Appraisal Skills Programme, 2013). Tables outlining the critical

appraisals of the articles can be found in Appendix 1. An overview of the articles included in this review is outlined in Table 2.2. They are listed in alphabetical order under separate sections for quantitative and qualitative studies. The majority of the articles were appraised as being of good quality. A few quantitative articles were appraised as fair and one qualitative article as poor. No articles were appraised as so flawed that they needed to be excluded from the review. The majority of the articles reviewed were observational studies, appropriate for the research aims of the studies but with limitations such as the inability to identify a causal effect.

Table 2.2: Overview of articles looking at the impact of MS on employment

Author/Year	Purpose of study	Study Method	Population	Findings/Conclusions
<b>Quantitative</b>				
Benedict et al, 2014	Validation of a vocational survey.	Cross-sectional survey, single clinical assessment.	N = 52 in USA (all employed).	Negative work events correlated with low performance on motor (p=0.02) and cognitive tests (p=0.03). Provided preliminary validation of work survey.
Bishop et al, 2013	Explore the extent that housing accessibility variables add to the prediction of employment in MS clients.	Cross-sectional questionnaire.	N = 4201 in USA, all of working age (part of a larger study of specialised housing needs).	Lower educational attainment, older age, increased years since diagnosis, increased physical disability, increased cognitive impairment, increased mobility limitations and several housing accessibility variables contribute to increased unemployment.
Bishop et al, 2015	Examined factors predictive of employment status change.	Cross-sectional questionnaire.	N = 4142 in USA, all of working age (part of a larger study of specialised housing needs, same population as above but only those of working age for both questionnaires).	Poorer physical function, older age, lower educational level and poorer cognitive function are all variables that contributed to unemployment.
Cadden and Arnett, 2015	Examined factors predictive of employment status change.	Cross-sectional, single clinical assessment.	N = 53 in USA (part of a larger study).	Poorer motor function, reduced cognition, increased levels of depression and increased fatigue significantly distinguished those who were unemployed versus employed.
Chiu et al, 2015	Explored the relationship between employment status, functional disability and HRQOL.	Cross-sectional survey.	N = 157 in USA.	Higher functional disability, increased levels of depression and lower HRQOL in those who were unemployed group compared to part-time and full-time employed.
Forbes et al, 2006	Explored the relationship between common MS problems and HRQOL.	Cross-sectional survey.	N = 929 in the UK.	Increased fatigue, increased pain, unemployment, increased levels of depression and relationship problems (all p<0.001) had a negative impact on HRQOL.

Abbreviations used in the table: MS – Multiple sclerosis, HRQOL- Health related quality of life, CI – Confidence interval

Author/Year	Purpose of study	Study Method	Population	Findings/Conclusions
Glad et al, 2011	Comparison of MS symptoms and their impact on employment.	Cohort clinical interview and examination.	N = 188 in Norway with relapsing-remitting (referred to as benign in this study) and progressive MS.	Employment in the benign MS group was 38.3% compared to 3.9% in the progressive MS group. Benign group scored significantly better on measures of depression ( $p < 0.001$ ) and fatigue ( $p < 0.001$ ).
Glanz et al, 2012	Measured work productivity in people with MS.	Cohort clinical interview and examination.	N = 377 in USA with isolated episode of MS or relapsing-remitting MS and part of an on-going study.	Absenteeism (work time lost) was not significantly associated with disease or patient reported outcome measures. Significant correlations between presenteeism (reduced work productivity) and increasing disability, fatigue ( $r = 0.71$ ; 95% CI 0.63-0.76), depression, anxiety and reduced quality of life.
Goverover et al, 2015	Factors that moderate activity and participation in people with MS.	Cross-sectional clinical interview and examination.	N = 72 in USA, part of larger study.	Unemployment associated with reduced cognition, increased fatigue, lower educational level, but not levels of anxiety, depression, disease duration or MS type.
Green and Todd, 2008	Examined social and economic impact of MS.	Cross-sectional survey.	N = 920 in the UK.	Employment issues are small component of study; MS has a negative impact on household standard of living due to employment issues.
Honarmand et al, 2011	Examined factors predictive of employment status change.	Cross-sectional clinical interview and examination.	N = 106 in Canada.	Progressive disease course ( $p = 0.041$ ), longer disease duration ( $p = 0.027$ ), being female ( $p = 0.032$ ), having depression ( $p = 0.014$ ) all had a strong association with unemployment.
Julian et al, 2008	Influence of disease stage, MS symptoms and demographics on employment rate.	Cross-sectional questionnaire.	N = 8867 in USA, pre-existing sample.	Increased fatigue ( $p < 0.01$ ), poorer cognitive performance ( $p < 0.05$ ), mobility changes ( $p < 0.05$ ) and reduced hand function ( $P < 0.0001$ ) - predictive of work loss. Unemployment increased from 56.2% to 58.9% in 1.56 years. Increase in symptoms in the past six months -significantly predictive of employment loss.
Krause et al, 2013	Effect of MS on employment status.	Cohort Clinical interview and examination.	N = 87 in Germany with MS and 37 matched controls.	Increased neurological disability, older age and increased fatigue (all $P < 0.001$ ) were independent predictors of a change in employment status.

Author/Year	Purpose of study	Study Method	Population	Findings/Conclusions
Krokavcova et al, 2010	Explore the association between self-rated health and employment status.	Cross-sectional clinical interview and examination.	N = 184 in Slovakia. Same population as below, but article focuses on measures of anxiety	People with good self-rated health ( $p < 0.031$ ) more likely to be employed.
Krokavcova et al, 2012	Explored the association between perceived health status and employment.	Cross-sectional clinical interview and examination.	N = 184 in Slovakia. Same population as above, but only focuses on health status	Being employed was an important factor in contributing to a better perceived physical and mental health status. More evident in a younger population group.
McCabe and de Judicibus, 2003	Study of the economic well-being of individuals with MS.	Cross-sectional questionnaire.	N = 113 in Australia.	Employment loss was predictive of increased costs. Individuals with more fatigue ( $p < 0.05$ ), tended to be unemployed, and had increased economic pressure.
Messmer Uccelli et al, 2009	Compared MS symptoms and employment status.	Cross-sectional questionnaire.	N = 1141 across Europe.	Increased MS symptoms (memory problems $p = 0.02$ , visual impairment $p = 0.004$ and mobility problems $p < 0.001$ ), significant association with unemployment. Flexible work schedule and financial security, key for promoting job maintenance.
Miller and Dishon, 2006	Impact of disability and employment on HRQOL.	Cohort survey.	N = 215 MS and 172 Healthy controls in Israel.	HRQOL is lower in MS clients than healthy controls ( $p < 0.001$ ) and this is more evident for unemployed MS clients.
Moore et al, 2013	Effect of clinical factors of MS on employment.	Cross-sectional questionnaire.	N = 221 in UK.	Higher disability level, lower education level, increased disease duration and increased fatigue strongly predictive of a change in employment status change ( $p = 0.032$ ).
Morrow et al, 2010	Investigated clinically meaningful cognitive decline and employment status.	Cohort Clinical interview and examination.	N = 97 in USA over 41 months.	Determined that a decline in cognitive function is associated with employment loss, and is also associated with higher EDSS scores and progressive forms of MS.
Morse et al, 2013	Effect of multitasking ability and fatigue on work.	Cross-sectional clinical interview and examination.	N = 30 in USA.	Increased fatigue ( $p = 0.005$ ) and decreased ability to multitask ( $p = 0.041$ ) in group who had cut back work hours.
O'Connor et al, 2005	Factors influencing work retention in MS.	Cross-sectional questionnaire and clinical assessment.	N = 62 in phase one and 100 in phase 2 in the UK.	Greater disability ( $p = 0.002$ ) in unemployed group. Also qualitative component present in this study.

Author/Year	Purpose of study	Study Method	Population	Findings/Conclusions
Pack et al, 2014	Effect of employment on quality of life.	Cross-sectional survey.	N = 1171 in USA.	Quality of life was higher in the employed group ( $p < 0.05$ ).
Patti et al, 2007	Effect of educational level and employment on quality of life.	Cross-sectional questionnaire completed in clinic setting.	N = 593 in Italy.	Quality of life was higher in the employed group ( $p < 0.0001$ ).
Phillips and Stuijbergen, 2006	Factors influencing employment.	Cross-sectional questionnaire at two different times.	N = 176 in USA, subset of larger sample.	Lower educational years and increased functional limitations ( $p < 0.05$ ) explained change in employment status over time.
Roessler et al, 2005	Effect of gender and perceived illness severity on employment concerns.	Cross-sectional survey.	N = 1310 in USA.	Women less likely to remain in the workforce than men.
Roessler et al, 2011	Discrimination influence on employment status.	Cross-sectional survey.	N = 200 employed MS clients in USA. Different study and population to above study	29.5% of the group had experienced discrimination including changes in work conditions and employers not providing reasonable job accommodations.
Salter et al, 2010	Impact of mobility on socioeconomic status.	Cross-sectional questionnaire.	N = 8180 in USA, pre-existing sample.	Mobility loss correlated negatively with employment ( $p < 0.0001$ ).
Shahrbanian et al, 2013	Impact of pain on employment status.	Systematic review and meta-analysis.	N = 10 studies (only 5 in meta-analysis).	Increased pain was significantly associated with decreased employment ( $p < 0.001$ ). Individuals with MS with pain, 70% at risk of unemployment.
Simmons et al, 2010	Reviewed employment status and reasons of employment loss.	Cross-sectional questionnaire in 2003 and 2007.	N = 667 in Australia.	56% lost work over a 4 year period. Most common reasons for leaving employment were increased fatigue (70%), mobility problems (44%), reduced hand function (40%) or cognitive deficits (37%).
Smith and Arnett, 2005	Effect of MS on employment.	Cross-sectional questionnaire and clinical assessment at two points in time.	N = 50 MS in USA 3 groups: working, cut-back hours and not working.	'Not working' group had significantly greater physical disability ( $p < 0.001$ ) than the other two groups and significantly more fatigue ( $p < 0.01$ ) than the working group. Concluded that physical disability and fatigue are major determinants of work status change.

Author/Year	Purpose of study	Study Method	Population	Findings/Conclusions
Strober et al, 2012	Factors that contribute to unemployment in people with MS.	Cross-sectional questionnaires and clinical assessment.	N = 101 in USA, part of a study on cognition.	Fatigue levels were higher in the unemployed group. Unemployed group were more neurologically impaired, had longer disease duration and tended to have a progressive course of the condition (p<0.001).
<b>Qualitative</b>				
Crooks, Stone and Owen, 2009	Explored what factors in an academic teaching environment supported participants to continue working.	Semi-structured telephone interviews. Thematic analysis.	N = 10 Academics with MS in Canada. Exploratory study	Travel, re-organising spatio-temporal routines and social networks were all strategies adopted to aid work. Limiting travel, having support of colleagues and family, re-organising office space and teaching schedule.
Crooks, Stone and Owen, 2011	Explored coping strategies employed by academics with MS to continue working.	Semi-structured telephone interviews. Thematic analysis.	N = 45 Academics with MS in Canada. Expansion of previous study, new participants	Need for flexibility in work based tasks. When teaching key changes needed to occur to enable work – use of teaching aids (assistant, computer); planning for rests after teaching; location of teaching sessions; sitting when teaching.
Johnson et al, 2004	The cost and benefit of employment in people with MS.	Semi-structured interviews Phenomological analysis.	N = 16 in USA.	Participants highly valued work and described the benefits of work. A cost of working was the curtailment of activities outside of work.
O'Day, 1998	Barriers to employment in people with MS.	Semi-structured interviews.	N = 16 in USA who were unemployed but wanted to work.	Increased fatigue, mobility problems, and an inability to write were reasons for leaving work and for remaining unemployed in the individuals. Societal barriers and issues around federal support systems - impacted on participant's ability to work.
Yorkston et al, 2003	Explored ability of people with MS to complete work activities.	Semi-structured interviews Phenomological analysis.	N = 14 in USA.	Fatigue was a prominent factor in the amount of activity that participants could do. Fatigue and cognitive changes were frequently associated with one another - more limiting than physical changes.

## Impact of disease characteristics on employment

### Fatigue

Fatigue has been found to be a principal predictor for employment status change for people with MS in a number of studies (Cadden & Arnett, 2015; Glad et al., 2011; Glanz et al., 2012; Goverover, Strober, Chiaravalloti, & DeLuca, 2015; Johnson et al., 2004; Julian et al., 2008; Krause, Kern, Horntrich, & Ziemssen, 2013; Moore et al., 2013; Morse, Schultheis, McKeever, & Leist, 2013; O'Connor, Cano, Ramio i Torrenta, Thompson, & Playford, 2005; O'Day, 1998; Simmons et al., 2010; M. M. Smith & Arnett, 2005; Yorkston et al., 2003). This may not be surprising when between 65% and 97% of people with MS experience fatigue, and up to 65% consider it to be their worst symptom (Mollaoglu & Ustun, 2009). Moreover, the 'invisible' nature of fatigue makes it difficult for others to understand and can lead to difficulties in personal and work relationships (Johnson et al., 2004; O'Day, 1998).

Higher fatigue levels are associated with unemployment. In a European cohort study of 87 people who underwent a clinical examination, fatigue levels were more pronounced in their unemployed group compared to the employed group (Krause et al., 2013). Another similar study showed that people with relapsing-remitting (known as benign in this study) MS with lower levels of fatigue had higher employment, compared to those with progressive MS with higher fatigue levels (Glad et al., 2011).

Some studies have also found that fatigue leads to people with MS reducing their work hours. In a study that compared two groups, the group that had reduced their work hours had higher fatigue levels than a group who had not (Morse et al., 2013), though the two groups had very different ages and disease durations. In another study, fatigue was again significantly higher in a group who had changed employment, with 61% of participants identifying it as a factor in them changing work hours, and 59% reported it as the reason for leaving work (Moore et al., 2013). Similarly, in one of

the few studies to look at participants over time, Smith and Arnett (2005) found that their 'not working' group had significantly more fatigue than their working group, while 90% of their 'cut-back hours' group reported that fatigue was responsible for their change in employment status.

Fatigue has also been found to be significantly predictive of work loss over time (Julian et al., 2008; Simmons et al., 2010). In a retrospective questionnaire that examined factors that influenced employment in over 8000 people, unemployment increased from 56% to 59% over 1.5 years, and an increase in fatigue in the past six months was significantly predictive of employment loss (Julian et al., 2008). This is further supported by the results of an Australian study that found the most common reason for leaving employment was fatigue, with 69% of those who lost employment over a four year period (from 2003 to 2007) attributing this work loss to fatigue (Simmons et al., 2010). Presenting at work when unwell, particularly when fatigued, can have a negative effect on work performance. This form of presenteeism (attending work when sick) was significantly correlated with fatigue but absenteeism (being absent from work when sick) was not (Glanz et al., 2012). Individuals in this study who had fatigue appeared to stay at work and struggled with performance rather than take the necessary time off work.

Qualitative studies have also concluded that fatigue impacts on work (Johnson et al., 2004; O'Connor et al., 2005; O'Day, 1998; Yorkston et al., 2003). In one of two studies using a phenomenological methodology, fatigue was a prominent factor and sometimes more limiting than physical changes in relation to work (Yorkston et al., 2003). It was closely associated with cognitive issues, either exacerbating cognitive problems or high cognitive based tasks causing fatigue. The other phenomenological study by Johnson and colleagues (2004) found fatigue was a significant barrier to employment and was described by participants as being profound, unpredictable and variable and was not apparent to co-workers. In two qualitative studies with no clear methodologies, fatigue was an issue in relation to work for 28% of participants (O'Connor et al., 2005) and it was a reason for leaving work and a major reason for remaining unemployed (O'Day, 1998).

A couple of studies reviewed found less association between fatigue and employment status. One study identified that all MS symptoms, including fatigue were significant factors in differentiating between their employed and unemployed groups, although there was no significant difference between MS symptoms and their relative influence on employment status (Messmer Uccelli, Specchia, Battaglia, & Miller, 2009). In another study, fatigue was again not found to be a significant predictor of unemployment (Strober et al., 2012), although fatigue levels were higher in their unemployed group. Even the findings of these two studies indicate that fatigue influences employment status and support the findings of the majority of studies reviewed.

### **Cognition**

There is some evidence that cognitive change is associated with employment status change for people with MS (Benedict, Rodgers, Emmert, Kininger, & Weinstock-Guttman, 2014; Bishop et al., 2015; Bishop et al., 2013; Cadden & Arnett, 2015; Goverover et al., 2015; Johnson et al., 2004; Julian et al., 2008; Krause et al., 2013; Messmer Uccelli et al., 2009; Moore et al., 2013; Morrow et al., 2010; Simmons et al., 2010; Strober et al., 2012; Yorkston et al., 2003). Interestingly, 65% of people with MS have cognitive changes (Rumrill Jr, 2009), although there may be issues with them recognising and reporting cognitive change and this may influence the findings of previous research.

In a questionnaire based review of a large sample, cognitive problems were found to be significantly predictive of work loss (Julian et al., 2008) and in a clinical review were also associated with negative work experiences (Benedict et al., 2014). Several studies found that lower levels of cognitive function, in particular changes in information processing speed and also verbal learning and memory were found in their unemployed group compared to those who were employed (Bishop et al., 2013; Krause et al., 2013; Morrow et al., 2010; Strober et al., 2012). Memory problems were again associated with employment changes; a study from the UK of 221 people with MS by Moore et al (2013) found that 36.7% of their sample reported they had led to a change in hours or work role and 35.3% reported them as the reason they left work. Similarly in other studies, people with MS

reported that they have left work due to difficulty with memory, concentration or thinking (Simmons et al., 2010) and that cognitive changes were a contributory factor to employment change (Messmer Uccelli et al., 2009). Indeed, over a 3 year period reduced cognitive function, in particular processing speed and verbal memory was the most consistent predictor of clinically meaningful functional decline and unemployment (Morrow et al., 2010).

In qualitative studies, a decline in cognitive function was reported as impacting on a person's ability to work and maintain employment and this was frequently associated with levels of fatigue (Johnson et al., 2004; Yorkston et al., 2003). Participants found that coping with cognitive changes required effort and was itself fatiguing and the experience of these issues was frightening to many of them.

Maybe due to problems in identifying cognitive issues, some studies found no association between cognitive change and employment status (Glanz et al., 2012; Honarmand, Akbar, Kou, & Feinstein, 2011; M. M. Smith & Arnett, 2005). These authors argued that cognitive change is often quite subtle in the early stages of MS and may not be detected with the tests and outcome measures used. The literature reviewed indicates that cognitive problems can influence employment status. The issues people with MS have recognising cognitive problems have likely influenced the conclusions of the literature to date.

### **Physical Changes**

Whether it be generalised physical changes or more specific mobility or hand function problems, physical disability impacts on the employment status of people with MS (Benedict et al., 2014; Bishop et al., 2015; Bishop et al., 2013; Cadden & Arnett, 2015; Chiu et al., 2015; Julian et al., 2008; Krause et al., 2013; Krokavcova et al., 2010; Messmer Uccelli et al., 2009; Moore et al., 2013; O'Connor et al., 2005; Phillips & Stuifbergen, 2006; Salter, Cutter, Tyry, Marrie, & Vollmer, 2010; Simmons et al., 2010; M. M. Smith & Arnett, 2005; Strober et al., 2012). The extent and type of physical changes vary widely among (and even within) people with MS (Rumrill Jr, 2009), and so the influence of physical changes on employment status is also likely to be quite varied.

A number of studies have reported on mobility changes being negatively correlated with employment status (Benedict et al., 2014; Bishop et al., 2013; Julian et al., 2008; Messmer Uccelli et al., 2009; O'Connor et al., 2005; Salter et al., 2010; Simmons et al., 2010). In a large observational study using a questionnaire in the USA, increasing levels of mobility impairment were associated with reduced employment in both full-time and part-time workers (Salter et al., 2010). Interestingly, the greatest proportional increase in unemployment occurred in ambulatory clients with mild loss of mobility (Salter et al., 2010). The use of a mobility device and reported mobility limitation were also significantly associated with reduced employment in a similar study (Bishop et al., 2013) and was the most important factor predicting employment status in a later study by the same researchers (Bishop et al., 2015). Mobility limitation has also been reported by 31% of participants in one study as a reason for a change in work hours or role; and 72% reported it as a reason for leaving work (Moore et al., 2013).

In addition to mobility problems, balance difficulties are also significantly associated with employment change (Messmer Uccelli et al., 2009; O'Connor et al., 2005). For example, balance impacted on the ability to work of 40% of the participants in the survey based study by O'Connor and colleagues (2005). Hand function problems have also been found to be predictors of work loss (Julian et al., 2008; O'Connor et al., 2005). Problems with handwriting (26%) were reported as impacting on the ability of participants to work (O'Connor et al., 2005).

Using the Expanded Disability Severity Scale (EDSS) (Kurtzke, 1983), a more generalised assessment of physical change, a number of cross-sectional studies found physical change to be a significant predictor of employment outcome (Krause et al., 2013; Krokavcova et al., 2010; Moore et al., 2013; O'Connor et al., 2005; Phillips & Stuifbergen, 2006; M. M. Smith & Arnett, 2005; Strober et al., 2012). People with higher neurological impairment and hence higher EDSS scores were more likely to be unemployed. In one of the few studies to review participants over a time period, a generalised decline in function was found to be a significant contributor to employment change over a seven

year period (Phillips & Stuifbergen, 2006). Those not working had significantly greater physical disability than people who were working or who may have cut-back their work hours. In another study, physical changes were reported by 30% of people who had stopped working and by 85.7% of people who had cut-back work hours; and was the reason for the work status change (M. M. Smith & Arnett, 2005).

### **Depression and anxiety**

There appears to be a correlation between depression and employment status for people with MS (Cadden & Arnett, 2015; Chiu et al., 2015; Glad et al., 2011; Glanz et al., 2012; Krause et al., 2013). This is hardly surprising given that depression occurs in 50% of people with MS, and may be a result of the neurological abnormalities or a psychological response to the diagnosis or disease progression (Rumrill Jr, 2009).

Depression was found to be associated with unemployment in people with all types of MS by some authors (Honarmand et al., 2011; Krause et al., 2013). However, Glad and colleagues (2011) found this association only in people with relapsing-remitting MS, while Glanz and colleagues (2012) found depression was associated with reduced work productivity in people with relapsing-remitting MS. Using logistic regression, depression was found to be related to employment status in combination with fatigue, motor function and cognitive issues but not in isolation (Cadden & Arnett, 2015).

Some studies have found no association between depression and unemployment (Krokavcova et al., 2012; Strober et al., 2012), although these studies demonstrated a correlation between employment status and anxiety, with participants who had low anxiety scores being 2.64 times more likely to be employed than those with higher anxiety scores. The lack of consensus reached from the literature reviewed is likely to be related to the variable presentation of depression and anxiety and also the challenges in accurately assessing these problems in self-rated scales.

## **Pain**

Two studies identified that pain was associated with employment change in people with MS (Moore et al., 2013; Shahrbanian, Auais, Duquette, Anderson, & Mayo, 2013). A literature review and meta-analysis found that people with MS who reported pain were 70% more at risk of unemployment compared to those who reported no pain (Shahrbanian et al., 2013). However, the authors did note that many of the studies reviewed did not identify the timing between the report of pain and the inability to work and so no causal relationship could be determined.

## **Duration of MS**

There was no conclusive evidence in the studies included in this review as to whether MS disease duration contributes to employment change in people with MS. However given the progressive nature of the condition it is not unreasonable to expect increasing problems with employment with longer disease duration.

Longer disease duration was found to be related to employment status, with the likelihood of employment reducing with each year following diagnosis (Bishop et al., 2013; Honarmand et al., 2011; Krause et al., 2013; Moore et al., 2013; Strober et al., 2012). Even in people with relatively low levels of disability, longer disease duration was found to be associated with unemployment (Honarmand et al., 2011).

This is in contrast to the findings of other studies which found no association between disease duration and employment status (Goverover et al., 2015; Krokavcova et al., 2010; M. M. Smith & Arnett, 2005). Glanz and colleagues (2012) reported that the duration of MS was not associated with employment issues but that higher EDSS scores and hence more advanced stages of MS were associated with reduced work productivity.

### **Type of MS**

There was inconclusive evidence on whether MS type influences employment status. A number of studies found that progressive disease courses have higher association with unemployment than other forms of MS (Glad et al., 2011; Goverover et al., 2015; Honarmand et al., 2011; Krause et al., 2013; Strober et al., 2012). Employment in people with relapsing-remitting MS was significantly higher (at 65%) compared to 17.2% in those with more progressive forms of MS, with people in the relapsing-remitting group also scoring significantly better on measures of depression and fatigue (Glad et al., 2011). In contrast, other researchers have not found MS type to be predictive of employment status change (Bishop et al., 2013; M. M. Smith & Arnett, 2005).

In summary, there is sufficient evidence to illustrate that MS specific factors such as fatigue, physical changes, depression, and pain are associated with employment change. There is less convincing evidence for the influence of cognition, disease duration or MS type. However, given that progressive forms of MS and longer disease duration are more likely to lead to more physical changes and other symptoms, it is not surprising that some studies found an association with employment change for these particular factors.

### **Impact of demographics on employment**

In addition to looking at disease-related factors that contribute to employment change, a number of studies reviewed demographic factors such as age, gender and educational level.

#### **Age**

Some studies have found that older age is associated with unemployment (Bishop et al., 2013; Glad et al., 2011; Krause et al., 2013; Moore et al., 2013; Simmons et al., 2010). The progressive nature of the condition is likely to mean that people with MS have more physical disability as their age increases and this may impact on their ability to work. Unemployed people with MS have been found to be on average 10 years older than their employed counterparts (Krause et al., 2013). A

study completed over four years (2003-2007) concluded that older people with MS are 1.3 times more likely to leave employment than younger people (Simmons et al., 2010). A younger age at diagnosis was found to be associated with a longer time until unemployment and this may be explained by younger people tending to be diagnosed with the relapsing-remitting form of MS (Glad et al., 2011). In contrast, no association was found between a person's age and their employment status in other studies (Krokavcova et al., 2010; M. M. Smith & Arnett, 2005; Strober et al., 2012).

### **Gender**

The evidence of the influence of gender on employment status in people with MS is inconclusive. Some studies have found that women with MS were more likely to be unemployed than men with MS (Honarmand et al., 2011), and that women tended to express employment concerns earlier in the disease progression than men (Roessler, Turner, Robertson, & Rumrill, 2005). It was also found that men tended to have more progressive forms of MS and reported increased severity than women, but despite this, seemed to maintain higher employment levels (Roessler et al., 2005). Roessler and colleagues (2005) concluded that other factors apart from disease severity may prevent women with MS from working.

However the opposite has also been reported, with women more likely to stay employed compared to their male counterparts (Phillips & Stuifbergen, 2006; Simmons et al., 2010). One study demonstrated, via logistic regression modelling, that men were in fact 2.5 times more likely to leave employment than women (Simmons et al., 2010). Other studies have found no difference in employment status between genders (Bishop et al., 2013; Glad et al., 2011; Krokavcova et al., 2010; M. M. Smith & Arnett, 2005).

### **Education level**

Educational attainment level has been found to be significantly associated with employment status change (Bishop et al., 2013; Glad et al., 2011; Goverover et al., 2015; Krause et al., 2013; Krokavcova et al., 2010; Moore et al., 2013; Phillips & Stuifbergen, 2006; M. M. Smith & Arnett, 2005). People

who had not completed high school education were approximately 78% less likely to be employed compared to those with a college degree (Bishop et al., 2013). Other studies have found that more years in education were a significant positive predictor of employment status (Glad et al., 2011; Krause et al., 2013; Krokavcova et al., 2010; Moore et al., 2013; Phillips & Stuifbergen, 2006), or that such individuals had better flexibility with their work hours and work roles (M. M. Smith & Arnett, 2005). Only one study found no association between educational level and employment status (Strober et al., 2012).

There are a number of reasons why people with higher educational levels may find it easier to remain in employment. A higher education level may be associated with a stronger awareness and knowledge of MS, better coping skills, and may mean a work role which is more flexible (Patti et al., 2007). Higher educational levels may lead to jobs with more flexibility and autonomy in modifying work role to meet the needs of the person with MS. Employers may also accommodate for workers who they view as talented and essential to the business (Rumrill Jr, 2009).

In summary, the demographic factors that seem to make it harder for people with MS to maintain employment are increasing age and lower educational level. Gender does not appear to have a consistent influence on employment status, and other factors may prevent women in particular from working.

### **Impact of contextual factors on employment**

Further to disease characteristics and demographic factors, a few studies examined how contextual or external factors such as the environment, diagnosis disclosure and discrimination impacted on employment status.

#### **Environment**

Although the influence of environmental factors on employment status has been seldom researched, the limited research reviewed does seem to indicate that there are environmental

factors that influence employment. Studies reviewed tended to explore strategies that had been adopted to maintain work and as a result identified some of the environmental issues experienced by people with MS at work.

Environmental issues were reported as the reason why 20% of people with MS had left employment in an Australian based study (Simmons et al., 2010). Issues with transport to and from work (13.6%), issues moving around the work space (17.4%), and the need for specialised equipment (20.7%) were reported as reasons for this employment change. Access to work and travel to and from work also impacted on the ability of people with MS to work (O'Connor et al., 2005). In a study reviewing the housing needs of people with MS, issues at home were also found to impact on work, with a need for assistance at home, home modifications and poor access to public transportation correlating with reduced employment (Bishop et al., 2013). People who did not require assistance at home were 1.3 times more likely to be in employment (Bishop et al., 2013).

A flexible work schedule, seated work, increased freedom in planning work schedules, a place to rest, freedom to take time off work, a stable and supportive workgroup, the use of appropriate equipment and resources, the immediate work environment and accessible transportation were all factors significantly associated with making work easier (Benedict et al., 2014; Johnson et al., 2004; Messmer Uccelli et al., 2009; Yorkston et al., 2003). Other strategies that enabled work included minimising travel on both a micro-scale (e.g. to and from work, within work) and also a macro-scale (e.g. to international conferences or work-related meetings) (Crooks, Stone, & Owen, 2009), as well as re-organisation of socio-temporal routines, such as reorganising room layout, and types of tasks completed. Two studies demonstrated that support from colleagues and other staff members facilitates work (Crooks, Stone, & Owen, 2011; Yorkston et al., 2003), as does support from family and friends for tasks at home. In a study of academic teaching staff, problem-focussed coping strategies enabled work; examples included teaching in rooms close to the office, use of teaching assistants, taking rest breaks, and teaching from sitting down (Crooks et al., 2011). It is evident that

small and inexpensive changes to the environment or the way tasks are approached facilitate people with MS to remain at work and could be applied to a variety of work settings (Crooks et al., 2011).

### **Disclosure and discrimination**

The limited literature exploring disclosure and discrimination and its influence on employment appears to indicate that people with MS can feel discriminated against when at work and this has been associated with diagnosis disclosure (Benedict et al., 2014; Johnson et al., 2004; Roessler, Rumrill, Hennessey, Nissen, & Neath, 2011). The decision to disclose a diagnosis of MS at work is not always straightforward. A qualitative study found that although many people with MS hoped disclosure would not lead to discrimination, many felt it had and found the need for ongoing disclosure with new staff challenging (Johnson et al., 2004). For example, 77% of people with MS who had disclosed their diagnosis to their employer felt they had been discriminated against in a study used to validate a recently created vocational survey for people with MS (Benedict et al., 2014). Discrimination included verbal reprimands, decreased work hours, diminution of job responsibilities and mandated retraining; and all were potential reasons for leaving work (Benedict et al., 2014).

Another study of discrimination claims in relation to new employment laws in the USA, found that 30% of employed or recently employed people with MS felt that they had been discriminated against at work (Roessler et al., 2011). The most common types of discrimination included failure by employers to provide reasonable job accommodations (48%); unfair working conditions, work environment, or employment privileges (44%); promotion denial or delay (41%); harsher standards of performance (39%); restriction in job type (32%); excessive supervision (30%); refusal to hire due to MS (29%); unfair wages (27%); forced retirement (27%); and unfair access to fringe benefits (25%). The study's participants reported that they tended to inform their employers and co-workers about the perceived discrimination, but rarely with a positive response, which had led to 28% of the participants in this study leaving work.

In summary, much of the research so far has focused on how the employment issues for people with MS may be related to person specific factors, such as disease characteristics and demographics. This would indicate that researchers believed that employment problems resided more with the person with MS rather than wider environmental and societal issues. However, the limited research into contextual factors such as the environment, and disclosure and discrimination, would indicate that these also make a contribution to the employment problems experienced by people with MS.

### **Consequences of employment status change**

A number of the studies reviewed looked at the consequences of employment status change; in particular their impact on quality of life, financial security and self-identity.

#### **Quality of life**

The literature indicated an association between employment status and health-related quality of life (HRQOL) (Chiu et al., 2015; Forbes et al., 2006; Krause et al., 2013; Krokavcova et al., 2012; Krokavcova et al., 2010; Messmer Uccelli et al., 2009; Miller & Dishon, 2006; T. G. Pack, Szirony, Kushner, & Bellaw, 2014; Patti et al., 2007). However due to the methodologies used and the high number of possible factors that could contribute to HRQOL, no causal relationship between employment status and HRQOL could be determined.

It was evident that employed people with MS tended to have higher HRQOL than those who were unemployed (Chiu et al., 2015; Krause et al., 2013; Krokavcova et al., 2012; Krokavcova et al., 2010; Miller & Dishon, 2006; T. G. Pack et al., 2014). In a study in the USA, people who were employed rated their HRQOL nearly a third of a standard deviation higher than their counterparts who were unemployed, although there was no difference between part-time and full-time employment (T. G. Pack et al., 2014). In addition to these findings, Miller and Dishon (2006) found that people with MS had lower HRQOL than a matched healthy control group and this appeared to occur even in the early stages of the condition. People with MS who are employed tended to also report good self-rated

health (Krokavcova et al., 2010). This influence was more evident in younger people (those under 45 years) than older people (over 45 years) (Krokavcova et al., 2012). Again a recent study from the USA found that participants who were unemployed had lower HRQOL, higher levels of depression and reduced life satisfaction than those who were employed in either part-time or full-time work (Chiu et al., 2015).

In a large study from the UK investigating the relationship between common MS problems and HRQOL, employment problems were found to have a negative effect on HRQOL, independent of the effect of disease (Forbes et al., 2006). The largest effect was found on the part of the HRQOL measure that looked at physical and social function, indicating that factors that contribute to employment problems may also impact on a person's ability to complete daily activities and their level of social interaction. Lower work productivity was also associated with lower HRQOL (Glanz et al., 2012). Employment status was again found to be an independent predictor of HRQOL (Patti et al., 2007). However this study had a very high percentage of employed participants (62.2%) and only included clients with relapsing-remitting forms of MS and hence possibly low levels of disability.

### **Financial**

A few studies have explored the financial issues associated with a change in employment status. It is not unreasonable to assume that the financial security offered by working encourages people to continue working, but is this sufficient to keep someone with MS working?

The financial benefits of working have been highlighted in the literature. Often it was not just the salary they received but also the benefits of health care and retirement plans that encouraged participants to continue working (Johnson et al., 2004; Messmer Uccelli et al., 2009; Yorkston et al., 2003). In an Australian study on economic well-being of people with MS, employment status was found to be a major variable in predicting increased costs and economic pressure for individuals with MS (McCabe & De Judicibus, 2003). In addition to the negative impact on the employment of the

person with MS, MS also impacts on the employment of others in their household, and this invariably had a negative impact on the household's standard of living (Green & Todd, 2008).

### **Self-identity and self-worth**

The influence of employment status on self-identity and self-worth seems to have been rarely explored but some studies have concluded that employment is important for preserving self-image and social confidence (Crooks et al., 2009; Simmons et al., 2010). In these studies, involvement in paid employment created a valued life role for individuals with MS (Crooks et al., 2009). Paid work gave individuals a chance to have personal and collegial relationships, develop personal and professional goals, and contributed to their sense of self-identity. As such, individuals were motivated to remain working because of these perceived benefits (Crooks et al., 2009). This has also been supported by qualitative studies that found that work was important to self-identity and self-esteem, as was the importance of social contact and a person's role within society (Johnson et al., 2004; Yorkston et al., 2003).

The research would indicate that the financial benefits of working are certainly likely to be a driving force for people with MS to remain in work. However, it may be the improvements in perceived HRQOL and the feelings of self-worth and social confidence that keep people working.

## **2.3 A need for further research**

Given the large variety of medical and psychological symptoms of MS, its unpredictable disease course, and its negative impact in every area of life, it is no surprise that employment issues are a significant concern for people with MS, and that unemployment rates are high.

This literature review has highlighted some of the reasons why people with MS leave work, usually of their own volition and often before the disease has rendered them incapable of working. Some studies have provided insight into the possible consequences of unemployment and there is some agreement on what factors contribute to employment change in people with MS, but for many

factors the evidence is inconclusive. Also, there are issues within the current literature that suggest the need for further research. In summary, issues in the current literature include:

- The research is principally from the USA and Europe. There are few studies from Australia and no studies from New Zealand. Therefore the findings from these studies may not be able to be extrapolated into New Zealand, because New Zealand not only has a different health system but also different employment law and different social services to support people at work.
- The current research uses a wide variety of methodologies and study designs, as well as different outcome measures and sub-populations of participants which may explain some of the conflicting results.
- There is a lack of longitudinal and cohort studies, so authors have been unable to make causal claims on factors and their effect on employment. It is also difficult to determine at what stage after diagnosis these factors started impacting on employment.
- The majority of research has focussed on person specific factors that may influence employment, with limited research exploring environmental and societal issues that may lead to employment issues.
- Very few qualitative studies have explored the experiences of people with MS and how it influences their work.

In summary, the literature reviewed in this chapter demonstrates that the relationship between disease-specific, demographic, and contextual factors and employment is complex and warrants further investigation, using research methods that can reveal and consider the experiences of those with MS (McCabe and De Judicibus, 2003; Yorkston et al, 2003; Johnson et al, 2004; Smith and Arnett, 2005). This type of research will provide a better understanding of the problems faced by people with MS, which could then help develop better interventions to allow people to manage their MS symptoms and facilitate employment. By managing MS and maintaining employment, the literature suggests that improvements in health-related quality of life and reduced economic burden

to individuals and society may occur. Therefore, this thesis intends to explore the experiences of people with MS who are at work, with the objectives being to shed light on their work experiences, and to identify what helps and hinders work.

## **Chapter 3 Methodology and Methods**

### **3.1 Overview**

The aim of this study was to explore the work experiences of people with MS. It is important to select an appropriate research process to address the aims of a research project. Therefore to explore a person's experiences, actions and processes in a social context, a qualitative study is required. Interpretative phenomenological analysis (IPA) was selected as the methodological approach for this study in order to capture the participants' own words about their experiences. Indeed, IPA lends itself well to research in which the intention is to explore lived experiences related to health and illness (J. A. Smith, 2011).

### **3.2 Interpretative phenomenological analysis**

IPA is a qualitative methodology and method that can be used to find out how people make sense of their experiences and the meanings they attach to these experiences (Cassidy, Reynolds, Naylor, & De Souza, 2011). It allows researchers to explore, describe, and interpret the way participants make sense of experiences (Dean, Smith, & Payne, 2006; J. A. Smith, Flowers, & Larkin, 2009) and so is very applicable to the aims of this research. Findings from IPA research can help to contextualise existing research, to improve understanding of novel or complex topics, or encourage reappraisal of existing knowledge (Brocki & Wearden, 2006).

IPA does not test a predetermined hypothesis; instead it intends to explore an area of concern in a more in-depth manner (Brocki & Wearden, 2006). IPA analyses the meanings an individual ascribes to their lived experiences of particular phenomena – in the case of this study, the lived experiences of people with MS in relation to their work. IPA has a strong theoretical foundation and a detailed procedural guide (Brocki & Wearden, 2006). By using IPA, I have committed myself to exploring, describing, and interpreting the ways the current study participants who have MS make sense of

their work experiences. The theoretical foundation of IPA is outlined in Table 3.1 and explained further in the text below.

Table 3.1: Summary of methodology and methods applied to this study

<b>Research question</b>	What are the lived experiences of people with Multiple Sclerosis who work?
<b>Methodology</b>	Interpretative phenomenological analysis (IPA)
<b>Epistemological position</b>	Constructivism – peoples’ meanings are socially constructed
<b>Theoretical perspective</b>	Phenomenological – explores the individuals’ lived experiences Hermeneutics – recognises the role of the analyst/researcher in the making sense of the participants’ accounts of their experiences. Idiography – offers detailed, nuanced analyses of particular instances of lived experience
<b>Methods – data collection and analysis</b>	Purposive sampling Semi-structured interviews Descriptive and interpretative analysis

### 3.3 Epistemological position

Epistemology is concerned with the nature of knowledge, and the legitimacy and meaningfulness of this knowledge (Braun & Clarke, 2013). Many qualitative research methodologies have a constructionist epistemological position, based on a belief that “truth, or meaning, comes into existence in and out of our engagement with the realities in our world” (Crotty, 1998, p. 8), rather than there being a single truth that resides in objects in the world, waiting to be revealed.

IPA moves beyond a pure constructionist position and instead embraces the concept of contextual constructivism (Larkin, Watts, & Clifton, 2006). A contextual constructivism position is that knowledge emerges from contexts, and also reflects the researchers’ positions, so is always specific to its context and the influence of the researcher (Braun & Clarke, 2013). This epistemological position behind IPA indicates that this is an appropriate methodology to use for this thesis, because I

am not aiming to find a single truth, but to explore the experiences of the current study's participants and to create a better understanding and knowledge of their particular experiences.

### **3.4 Theoretical perspective**

IPA is underpinned by three key theoretical perspectives, phenomenology, hermeneutics and idiography (J. A. Smith, 2011). These perspectives are not unique to IPA, but the way IPA combines them and places specific emphasis on them has created a distinct methodology.

#### **Phenomenology**

IPA is phenomenological as it is concerned with the detailed examination of human lived experiences, and is expressed in the terms of the person experiencing a particular moment of significance to them (J. A. Smith, 2011). Phenomenology is a philosophical approach to the study of experience. In particular, it focuses on what matters to us as humans within our lived world. The evolution and development of phenomenology has been influenced by four principal philosophers: Husserl, Heidegger, Merleau-Ponty and Sartre (J. A. Smith et al., 2009). Although these philosophers were diverse in their interpretation of phenomenology, it is a combination of their theories that underpins IPA and which has led to a more holistic approach to phenomenology (J. A. Smith et al., 2009).

Husserl's work was concerned with finding the essence of experience; he supported an attentive and systematic examination of our lived experience. Husserl's work influenced IPA by encouraging IPA researchers to focus on the process of reflection, attempting to capture particular experiences as experienced by particular people (J. A. Smith et al., 2009). Husserl introduced the term 'bracketing', the concept of isolating the researcher's past experiences and presuppositions from their perception of an experience. Bracketing was encouraged because Husserl believed that the true meaning of an experience could only be understood by perceiving an experience of a phenomenon in its original

form, and that any preconceptions and biases from others (for example, the researchers) contaminate this perception.

Heidegger, Merleau-Ponty and Sartre's approach to phenomenology support a view that a person and their experiences are embedded in and influenced by the world in which they live. The work of these philosophers has created the phenomenological basis of IPA; that the understanding of experience is related not only to a person's embodied lived process but also to their relationship to the world and aspects of their interpretation of it (Cassidy et al., 2011).

IPA demonstrates phenomenological perspective by paying close attention to a person's experience, and by encouraging him/her to tell their own story in their own words (J. A. Smith et al., 2009). It intends to reveal any subject matter in its own terms and not be influenced by preconceptions or biases (Larkin et al., 2006). This can be challenging and researchers can fall short of this target, because they are also a 'person in context', and therefore cannot altogether escape the preconceptions their world brings with them. IPA acknowledges that it can be challenging to 'bracket' and so instead the researcher is actively encouraged to acknowledge and reflect on the things that influence their perceptions of a phenomenon.

### **Hermeneutics**

Hermeneutics is the theory of interpretation and is the second theoretical perspective influencing IPA (J. A. Smith, 2004). Hermeneutics recognises the role of the researcher making sense of the participant making sense of their personal experiences (J. A. Smith, 2011). It is interpretative as it is influenced by the researcher's own beliefs and experiences.

In IPA an inductive approach is promoted, recognising that the interpretation is co-constructed between the researcher and the person being researched and will be influenced by values, preconceptions and assumptions (J. A. Smith et al., 2009). Interpretative analysis helps find

meanings beyond the immediate claims of the participants; it reveals more about a person than that person may be aware of themselves (Cassidy et al., 2011).

As in phenomenology, there is also support for 'bracketing' in hermeneutics, the need to 'bracket' the researcher's current understandings in order to understand the experience of the participants first hand. IPA acknowledges that it can be hard to bracket these preconceptions, especially as they may not come to light until completing the research (Cassidy et al., 2011). Smith et al. (2009) suggest that it is not always possible to bracket all preconceptions throughout the research journey and so encourages reflective practices and a cyclical approach to bracketing.

A key IPA concept is the hermeneutic circle; the dynamic and circular relationship between the part and the whole. If you are to understand a part of an experience, you need to understand the whole experience, and to understand the whole experience you need to understand the parts. In fact, IPA is an iterative process moving backwards and forward through the data, to analyse and interpret it. A double hermeneutic circle exists in IPA research as the researcher makes sense of the participant making sense of their experience (Rodham, Fox, & Doran, 2013). The researcher wants to understand what it is like from the participant's view, but also wants to look at it from another perspective, creating the more interpretative component of IPA (J. A. Smith, 2004).

### **Idiography**

The third theoretical perspective underpinning IPA is idiography, an interest in the particular. In IPA, idiography operates at two levels. Firstly, thorough and systematic analysis creates a sense of detail and depth to the analysis showing, a commitment to the particular (J. A. Smith, 2011). Secondly, IPA is committed to the particular, through understanding a particular phenomena (work experiences in this study) understood from the perspective of particular people (individuals with MS), in a particular context (New Zealand). The ideographical underpinning of IPA means that it can offer detailed, nuanced analyses of particular moments of lived experiences.

IPA starts with detailed analysis of each case, before moving onto analysis of the next. Through dynamic bracketing, the researcher attempts to prevent the findings of each individual case from influencing their interpretation of the next case. This helps maintain each person's unique story (Cassidy et al., 2011). Finally a cross-case analysis is completed to create more general analysis and claims, exploring for instances of convergence and divergence (J. A. Smith, 2004). The act of moving from the particular to the general is founded on the idea that each individual does indeed have a unique interpretation of an experience.

It is the influence of these three theoretical perspectives that mean IPA findings will always be indicative and provisional rather than absolute and definitive (Cassidy et al., 2011). IPA does not intend to produce generalisable results; its inductive nature allows researchers to discuss their analysis in context to existing theories and knowledge (Brocki & Wearden, 2006). The hermeneutic perspective moves IPA away from being a purely phenomenological methodology, the emphasis on interpretation creates findings that are not just simple descriptions of experiences but a deeper understandings of the phenomenon that are context specific and also influenced by the sense making of both the individual and researcher (Clarke, 2009).

In summary, it is the epistemological position and the theoretical perspectives behind IPA that make it an appropriate methodology for research exploring people's experiences in a particular context, and as such is an appropriate methodology for this study. The recognition of the dynamic role that the researcher plays in the data interpretation also supported me to choose this methodology due to my dual clinician/researcher role.

### **3.5 Method for collection and analysis of data**

Having outlined the epistemology, theoretical perspectives, and methodology for this research study, I will now outline the methods used to collect and analyse the data for this study.

## **Ethical approval**

Ethical approval for this study was provided by the University of Otago Human Ethics Committee (Health) in May 2015 (H15/037 – see Appendix 2). Included in the application for this approval was evidence of my consultation and the approval I gained from ‘Multiple Sclerosis and Parkinson’s Canterbury’ to recruit participants via their organisation.

## **Participant recruitment**

As recommended in IPA, the study’s recruitment was by way of purposive homogenous sampling (Brocki & Wearden, 2006; Clarke, 2009; J. A. Smith et al., 2009). Participants who were likely to be the most relevant to the research aim were selected, since in IPA it is encouraged to select cases to illustrate a particular research question and to develop an interesting interpretation of the data (Clarke, 2009; J. A. Smith et al., 2009). To create a purposive homogenous sample, inclusion criteria were created for this study. To be included in this study, participants needed to have a confirmed diagnosis of MS and be working in paid employment or have worked in paid employment in the last six months. People who had stopped working within the last six months were within the inclusion criteria, to help facilitate an adequate number of participants for the study. Those who had not worked in paid employment within the last 6 months were excluded, as they may have struggled to recall their experiences in relation to work. Those completing voluntary work, study or who were principal carers/housewives were also excluded, as they may have had very different experiences to those in paid employment. Participants with cognitive, speech or language issues were excluded as they may have found it hard to express themselves in interviews; the chosen data collection method for this study.

All the participants were recruited from within the membership of ‘Multiple Sclerosis and Parkinson’s Canterbury’, an organisation supporting people with the two conditions in Christchurch, New Zealand. A flyer (see Appendix 3) requesting volunteers was mailed out with a quarterly newsletter to all members with MS. Potential participants responded to the flyer or were

approached by a third person (the MS nurse, not otherwise involved in the study) to see if they would be interested in the study. On expression of interest, potential participants were sent an information sheet (see Appendix 4) by the lead researcher. Further communication with the lead researcher via phone or email enabled potential participants to clarify information, ask further questions, and confirm their interest.

Due to the in-depth interpretation of participants' experiences, there is a consensus towards the use of a smaller sample size in IPA (Brocki & Wearden, 2006; J. A. Smith et al., 2009). Therefore it was hoped that between six and ten people could be recruited for the study. Selection of the final nine participants was based on the inclusion and exclusion criteria. More women were selected than men, as more women had volunteered for the study but is also in keeping with the gender distribution of MS.

Selected participants were contacted by phone to arrange a time and date for an interview to be conducted with them. At the time of their interviews, all participants signed a written consent form (see Appendix 5) prior to the start of the interview.

### **Data collection**

In keeping with IPA, data was collected in such a way as to enable each person's experiences to be expressed in his or her own terms (Dean et al., 2006). This is commonly done with the use of semi-structured interviews (Biggerstaff & Thompson, 2008; Brocki & Wearden, 2006; Clarke, 2009; Larkin et al., 2006; J. A. Smith, 2011; J. A. Smith et al., 2009) and this was the data collection method for this study. Semi-structured interviews facilitate rapport with participants and allow greater flexibility to explore novel directions and experiences (Brocki & Wearden, 2006; J. A. Smith, 2004). The questions for the semi-structured interview were based on the literature review around MS and employment (detailed in chapter 2); and from discussions with other clinicians who work with clients with MS and also the thesis supervisors. As suggested by Smith (2004), the questions were open

ended, singular and non-directive. A copy of the interview schedule is included in Appendix 6. This also included a selection of possible prompt questions that were used at times to facilitate the participants to answer the questions or to explore areas of interest in further detail. The initial questions within the schedule were broad to help facilitate rapport and help gain a clear understanding of the participants' backgrounds.

Prior to the first participant's interview, I was interviewed by one of my supervisors as an opportunity to experience how to complete a qualitative style interview. Using my interview schedule as a guide, my supervisor asked me to share what responses I expected to the questions and the reasons why I expected these responses. This pre-supposition interview allowed me to self-reflect, and become aware of possible pre-conceptions and knowledge that I needed to endeavour to 'bracket' prior to the study interviews and analysis. While also familiarising myself with how to complete a semi-structured interview, it helped me develop my awareness of possible relevant concepts that may be expressed in the interviews and gave me time to explore if the interview schedule was likely to facilitate discussion of relevance to the research topic.

The time and date of the interviews were at times selected as the most convenient by the participants. Interviews occurred in locations familiar to and selected by the participants in order to help facilitate discussion. Some interviews occurred in the participants' homes, others at their place of work and some at the 'Multiple Sclerosis and Parkinson's Canterbury' centre. The interviews lasted between 40 – 85 minutes.

My supervisors and I reviewed the audio recording of the first interview and suggestions were made to help refine the interview schedule and interview technique. This also facilitated further self-reflection and 'bracketing'.

As recommended for IPA studies (Brocki & Wearden, 2006; Larkin et al., 2006; J. A. Smith et al., 2009), the interviews were digitally audio-recorded, and then transcribed verbatim. The transcribing

was completed by an externally contracted typist. Identifying information was removed from the transcripts (e.g. names of people, and places) and pseudonyms were given to each participant to help maintain confidentiality and anonymity. Appendix 7 outlines the transcription conventions used. All written documentation for the study was stored in a locked cabinet, and electronic documentation was kept on a password secured computer. Basic demographic information was collected for all participants; this included age, gender, type of MS, years since diagnosis, type of work and hours of work.

### **Data analysis**

IPA uses a cyclical iterative process of data analysis (Brocki & Wearden, 2006) in which the researcher approaches the analysis idiographically, beginning with particular examples and slowly working up to more general categorisations or themes. Researchers using IPA try to avoid being too prescriptive about the data analysis phase, but key components include the need for in-depth immersion in the data, an iterative and cyclical approach, and maintenance of attention to the idiographic nature of the data (J. A. Smith et al., 2009). Table 3.2 outlines the stages of analysis for this study as recommended in IPA (Biggerstaff & Thompson, 2008; Brocki & Wearden, 2006; Cassidy et al., 2011; Finlay, 2014; Larkin et al., 2006; Rodham et al., 2013; J. A. Smith, 2011; J. A. Smith et al., 2009).

It was important in the initial descriptive phase of data analysis to create an understanding of the participants' worlds, and to describe what it was like for them as if it was the first time I had come across such descriptions. Later analysis was more interpretative, positioning the initial descriptive analysis in relation to a wider social and cultural context. This interpretative analysis provided a critical and conceptual commentary upon the participants' personal sense-making activities. For the discussion section of this study, the themes were reviewed alongside the findings of previous research, in order to find support for or argument against my interpretative analysis.

Table 3.2: Stages of analysis in this study

Stage	Action	Rationale
1	Bracketing - Journaling, recording my own knowledge, reactions and thoughts before and after interviews, and throughout the analysis process.	To create a clearer understanding of my perceptions, to 'bracket' these during the interview process and in the early analysis phase. To assist in the later interpretative analysis stage.
2	Transcription of digitally recorded interviews by a typist.	To create written text for analysis.
3	Transcripts reviewed and corrected, while listening to the digital recording.	To check for transcript accuracy and increase immersion in the interview data.
4	In-depth analysis of hard copy versions of transcripts, line by line annotating points of interest as codes. Each interview was also reviewed by one of the supervisors who annotated it with points of interest. Each interview was discussed at a supervision session.	Initial descriptive analysis, creating an understanding of the participants' experiences.  To help establish rigor in this study. Aimed at developing consensus rather than absolute agreement.
5	Analysis codes for each interview added to NVivo 10 (QSR International).	Use of computer software to help manage and organise the analysis of qualitative research.
6	Codes from the interviews were combined and condensed into themes in Nvivo 10. Also using paper based clustering to develop themes further.	Ongoing analysis (conceptual and interpretative), looking for convergence and divergence across themes, developed understanding of themes.
7	Re-reading of transcripts and listening to interviews.	Ensured focus on emerging themes connected to the individual experiences of the participants, remaining grounded and attentive to text of transcripts (Idiographic component).
8	Use of diagrams, discussions with peers, colleagues and supervisors; and reflective accounts to develop themes.	Development and clarification of main themes.
9	Re-reading transcripts.	Ensured focus on emerging themes connected to the individual experiences of the participants (Idiographic component).
10	Development of narrative description of themes for results section. Selection of extracts from transcripts to illustrate themes.	Assisted to develop themes and created a deeper level of interpretation, ensuring that interpretations are grounded in the participants' accounts and not imposed on them.
11	Development of discussion chapter, reviewed existing literature and searched for additional literature in connection with emerging themes.	Examined themes alongside findings from existing literature.

In IPA studies, researchers are encouraged to demonstrate reflexivity as part of their 'bracketing' process (Biggerstaff & Thompson, 2008; Brocki & Wearden, 2006; Clarke, 2009; Rodham et al., 2013). Due to my dual clinical/researcher role in this study, it was difficult for me to fully bracket all my previous experience and understandings. I had naturally formed preconceptions because of the time I had spent working with people with MS and particularly from providing assessments and interventions to some of my study participants in the past. Instead I was reflective and critical of my preconceptions and understandings throughout the research journey. As suggested by Rodham and colleagues (2013), I employed a curious perspective, assuming that I did not understand or know the issue of study so as to be better able to question my prior knowledge and experience. I did this through reflexivity, becoming mindful of my role in the creation of the study's findings. From the development of the research proposal, through to the writing up phase, I have kept a reflective journal, notes/memos and drawn diagrams to demonstrate reflexivity and transparency. These writings were a way for me to engage in the process of thinking critically about my involvement and influence on the research and preserve emerging ideas and theories in the data analysis phase. Reflexivity was also supported by sessions with my study supervisors for discussing and reviewing my progress, analysis and interpretations. As well as supporting reflexivity, having each transcript reviewed by one supervisor and discussing analysis of each transcript at supervision sessions also informed the scientific rigor of the study. This peer-coding was aimed at providing consensus rather than absolute clarity (Brocki & Wearden, 2006). The scientific rigour of this study has been further demonstrated by clearly outlining the study's methodology; accurately describing the sample from which the data was collected and all sources of data collection.

### **3.6 Ethical considerations**

Prior to starting the study, possible ethical issues were identified and are discussed further below. Sessions with my thesis supervisors allowed me an opportunity to address ethical issues that developed throughout the study,

## **Role of the researcher**

IPA recognises that the researcher is central to the analysis and as such should acknowledge their influence in the research (Brocki & Wearden, 2006). Reflexivity as outlined above and the role of the researcher in the interpretation of the data is key (Brocki & Wearden, 2006; Dean et al., 2006). While being both the lead researcher in this study and the person who conducted the interviews, I was also a physiotherapist at 'Multiple Sclerosis and Parkinson's Canterbury' and as such had provided clinical input to the participants in the past, and for some also during the course of the study. While I believe this assisted the rapport developed in the interviews and also the depth of data obtained, there was also a potential for confusion and issues around boundaries. Participants may have felt obliged to participate due to their past or current relationship with myself; therefore to minimise this issue, a number of conditions were agreed before starting the study. Participants for the study would not be directly recruited by myself; instead they either volunteered to take part after receiving a mailed out advertisement for the study or after being contacted by a third party, the MS nurse. Participants were also clearly informed that they could withdraw from the study at any point without it negatively affecting their health care and could also request to have clinical support from the other physiotherapist at 'Multiple Sclerosis and Parkinson's Canterbury' if they preferred. There were regular discussions in my supervision sessions regarding any potential conflicts because of my dual researcher/clinician role.

## **Impact on participants**

Both within the participant information sheet and also prior to their interview, participants were advised that they could decline to answer any questions or to withdraw from study. Prior to starting the study it was identified that participants may become upset or distressed in the interviews. It was therefore planned that if the participant felt it was needed, the interview could be stopped. Indeed, one participant did become emotional during their interview, but was quickly able to continue with

the interview after a brief pause. When this person was asked if they needed any support at the end of the interview, they reported that they were fine and did not require any additional support.

A possible ethical issue identified before the study, was how to support participants who sought clinical advice or input during the course of the interview. It was agreed that if the participant sought advice on a particular issue, I would not address the issue within the interview but after the interview suggest they make an appointment with me or a health professional colleague to address the issue. No participants in this study sought advice in the interview and no follow up appointments to address issues raised were required.

### **3.7 Summary**

The aim of this study was to explore and create a better understanding of the work experiences of people with MS. To address this aim, a qualitative study was required. IPA was chosen because of its commitment to exploring and interpreting the means by which people make sense of their experiences. The theoretical perspectives of IPA and its epistemological perspectives have been outlined. A purposive homogenous sample of people with MS was selected and they participated in semi-structured interviews. In-depth data analysis in keeping with IPA strategies was undertaken. The following chapter presents the results of this data analysis.

## **Chapter 4 Results**

### **4.1 Participants characteristics**

Seventeen people volunteered for this study. Nine were selected based on the study selection criteria and to create a relatively homogenous sample. Demographics for the group are outlined in Table 4.1. Six women and three men with an average age of 43 years were interviewed. Seven of the participants had been diagnosed with relapsing-remitting MS, with two of these going on to develop secondary progressive MS, and the remaining two participants having primary progressive MS. The duration of time since onset of MS for the participants ranged from three to 17 years. Participants worked across a variety of occupations, although all worked in professional capacities rather than, for instance, in manual labouring. All had at least a tertiary level education.

The group reported a variety of fluctuating symptoms related to MS. These included fatigue, changes in vision, mobility and balance problems, bladder and bowel issues, cognitive and communication problems, and issues with pain and muscle spasm. Fatigue was one of the most frequently expressed problems and was often exacerbated by physical and cognitively demanding tasks. Increasing fatigue levels made MS related symptoms worse, and so fatigue was frequently associated with a vicious cycle of worsening symptoms.

Table 4.1: Study participants' demographics

<b>Gender</b>	Six women and three men
<b>Age</b>	Average 43 years (37-53)
<b>Type of MS</b>	Relapsing remitting MS (n=5), secondary progressive MS (n=2), primary progressive MS (n=2)
<b>Duration of MS</b>	7 years (3-17)
<b>Educational type</b>	All tertiary level
<b>Occupations</b>	Teacher/Educator/Researcher (n=3), account managers (n=5), health professional (n=1)

## 4.2 Results overview

This chapter outlines the analysis of the participants' interview transcripts. The participants shared a wealth of information about their experiences of working, with their common experience being that of making work changes. The participants moved through a journey of change, first with the diagnosis of MS and then as part of their work experience.

Running throughout all the participants' stories were four main themes:

1. *'Challenge'*
2. *'Choice and control'*.
3. *'Preparation for change'*
4. *'Consequence of change'*

All of the participants had experienced a variety of challenges since developing MS, and many of these were directly connected to work and making work based changes. The participants strongly believed in the need to make their own choices and be in control of their work life, particularly as they already faced the uncertainty of living with an unpredictable and progressive condition. A variety of catalysts triggered work changes and several factors influenced the participants' preparation for change. The participants experienced both benefits and demands as a consequence of making work changes.

There was a strong connection between all these themes, as is represented in Figure 4.1. The themes of challenge, choice and control ran throughout the participants' experiences of preparation for change and consequence of change. The challenge, choice and control themes will be explained in separate entities but will also be further explored as the themes of preparation and consequence are discussed.

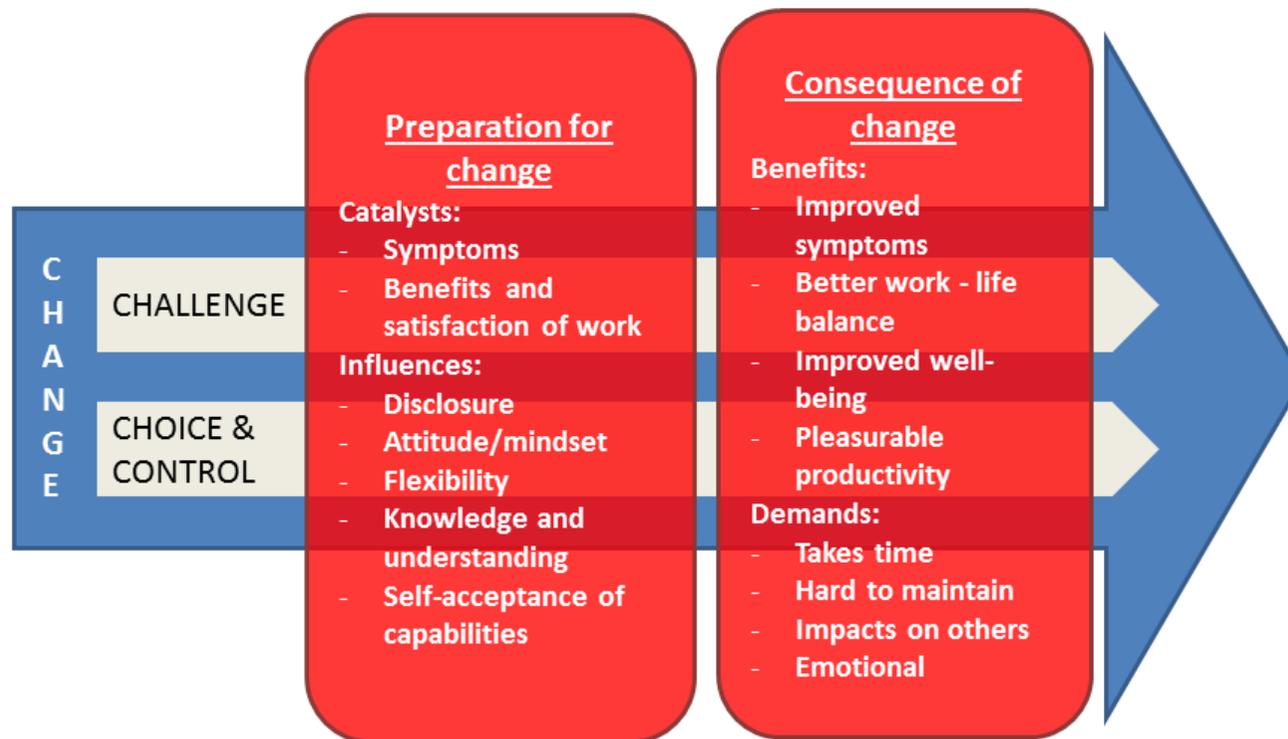


Figure 4.1: An on-going journey of change – transitions in work for people with MS

### **4.3 Change**

Change is an inevitable part of everyone's lives but especially for people living with a chronic health condition. All the study participants had made changes in their lives since being diagnosed with MS, including changes to help them continue working. For some this had been a small change such as scheduling their work day differently, but for others it had been a more significant change, such as finding a new career. Recognising the need to change and to make changes was a challenge for many of the participants. They felt driven to take control, and to make their own choices which aided them to continue working. In order to prepare for change, the participants needed to recognise catalysts for change such as variation in their MS symptoms and also alterations in their work performance. The process of change was influenced by a variety of factors, some within the control of the participants and others not. There were benefits from making changes but the participants also felt increased demands on themselves and others because of the implementation of changes.

### **4.4 Challenge, choice and control**

#### **Challenge**

All the participants had experienced challenges since being diagnosed with MS. Living with MS had made work more challenging for the participants. These challenges impacted on their ability to recognise the need to make changes, and to decide what changes would be appropriate to make in relation to their work.

A common challenge for the participants was accepting their MS diagnosis and the onward disease progression. Several participants shared how they struggled to accept their MS and the uncertainty associated with a condition with a variable rate of progression.

*It's a realising that you have actually got something wrong with you, when you don't want to. And it's the unknown thing with MS, which is probably the hardest thing for anybody.*

*(Wendy)*

The unpredictability and variability of symptoms meant that it was difficult to cope with living with MS. The fact that the condition is incurable also made it harder for the participants to live with the diagnosis. Sarah described the diagnosis as being like 'a bullet to the head', thereby expressing in a vivid way the huge impact her MS diagnosis had had on her.

The participants were challenged to cope with a variety of emotions in relation to living with MS. They experienced a grieving process not only when diagnosed, but also at other times while living with their condition. Some participants described an emotional journey with many ups and downs. When Emily had had a relapse she had needed to take time off work to grieve. Having to make changes at work was an emotional low point for many of the participants, and even more so when it meant giving up on a previous career pathway. Melissa had recognised that she could no longer be a researcher because of her MS, but even after making a career change, the emotions of this change were still raw.

*Because of that reality [very emotional tone of voice]. There's no point in going, right, I'll keep doing what I was doing as a researcher, because it wasn't [crying] –* (Melissa)

A frequently expressed emotion was frustration. Participants felt frustrated about not being able to do things at home and work as they used to because of their MS. They also felt frustrated at the need to make changes.

*I didn't realise how frustrating it would be to try and change your work. I mean like for my job, there's heaps of different avenues of work, but I've found it really frustrating just trying to change.* (Susan)

The emotional and psychological impact of the diagnosis and the evolving condition made it hard for participants to work. They described how it took more effort for them to work than it would for others. Even to get to work on some days was a real challenge. Participants also found it challenging to come to terms with their changing ability at work and they found it hard when they could not perform at their previous capacity.

*I love what I do, I just don't get to do as much of it these days. And that's part of the frustration. (Wendy)*

One of the main challenges they faced at work was simply dealing with the changes required, and for some, this made them insecure in their work. Many participants voiced awareness that it would become harder and more challenging for them to work as their MS progressed. The uncertainty of the MS progression meant that they felt unsure about their future capacity for work, and so many of them felt unable to make future plans.

*Yeah. I don't have as many ambitions within my role as I would have done before. I am very happy in the role that I'm in, I want to make the best of it, and I have certain things within that I want to do, but I'm not aiming to be X, Y, Z. So work- work is work. (Melissa)*

Despite these challenges, the participants felt it was important to keep working. So even with work getting harder as their MS progressed, many identified that they would simply have to change and adapt in order to continue working.

*Without a doubt. And it will become harder and harder, but you just adapt. For sure, don't ever stop. (Peter)*

## **Choice and control**

The notions of choice and control fit together as one theme. Participants shared how they felt driven to take control of their lives and the choices they could make because they felt they did not have

control of their MS. This was particularly evident when the participants talked about the changes they had made at work. Participants seemed more positive about change if they felt they themselves had chosen those changes, or had been consulted about making changes. In contrast, the participants who felt that changes were enforced on them by others felt more frustrated and upset by these changes.

*And that was one of the big stumbling blocks when I stepped aside, was that we made all these changes, because I wasn't coping, and it was a head office decision, to say 'hey look, [Wendy], you're doing too many hours, you're taking on too much stress, let's make it easier for you, this is what we think should happen.'* (Wendy)

Similarly, Susan's bosses had made changes to her job, leaving Susan feeling like she had lost control, which made her feel out of control within her work, and stressed.

*I would rather have a little bit more stability but at the moment, that's what I've got ... I don't think it's a positive thing, to have the unknown and the stress, cause you can't kind of – I mean there's a lot of stuff that's out of your control with MS anyway.* (Susan)

For the participants to make positive choices about their work changes, and therefore to feel empowered, they recognised that they needed to be realistic about their work capacity in relation to their changing MS symptoms. For some this meant changing their beliefs and mentality about their lives. They also recognised the need to plan for the future, making some changes before they were absolutely necessary. To better manage her MS, Sarah had needed to alter her beliefs to make changes and start planning for the future.

*So it's that management of which it's something that only really I can do. And it's getting my head around it. Yeah. And it's what does [Sarah] want to do? And where does [Sarah] want to be in the next five, ten, fifteen years?* (Sarah)

## **4.5 Preparation for change**

In preparation for work changes, participants first had to recognise the need to change. Catalysts for change included their MS symptoms and also alterations within the participants' satisfaction of work. In addition, the participants' acceptance of the need to change and ability to change was influenced by a variety of factors. The factors that the participants had control of included disclosure of their diagnosis at work, their attitude to the diagnosis of MS and its relation to their work, and their self-awareness of their own work capabilities. They had less control over the flexibility of their work role and the understanding of others.

### **Catalysts**

There were a variety of catalysts that made the participants make work changes. Some participants had come to a crisis point in their work, often where they were struggling to perform in the role and this had led to associated dissatisfaction with their work.

Symptom changes resulting in mobility and balance issues, issues with fatigue, altered vision and difficulties with communication impacted on the participants' ability to work and were catalysts for them to make changes. Although less recognised and acknowledged by the participants as an issue, cognitive changes were clearly a problem for some participants, and had led to work based changes.

Mobility and balance changes often made it hard for the participants to get to work and then to move around the work place. Balance was also an issue in relation to falls, with many of the participants describing strategies they used to prevent themselves from losing balance and avoiding the embarrassment of falls. These issues had led to changes in some participants' work roles, and for others this had been the reason for them to seek new work. The decline in Peter's mobility had been one of the reasons for leaving his previous job.

*Yeah, I mean, I was working in [name of company], but it was, the job was getting incredibly boring, and physically it was getting quite difficult too, because it's a lot of standing, and walking round factories and stuff. And in my current state, there's no way could have done it.* (Peter)

As well as making getting around difficult, mobility problems also created barriers for the participants to feel socially connected to their work colleagues. Dependent on the location of work-based activities and social occasions, participants had often felt unable to attend because of their mobility restrictions. For example, Susan felt left out as she was unable to join her colleagues for coffee. For some participants this loss of social connection at work had led them to feeling dissatisfied within their work and this drove them to make changes.

*Sometimes you kind of feel a little bit left out on somethings, like with work, you know, they'll say 'Oh, we're going to...walk into town to get a coffee or lunch, do you want to come in with us?' I'm like 'Well, how far is it?' 'Oh, it's not too far.' 'Well [I thought], that might not be too far for you, but that's a wee way for me.'* (Susan)

Fatigue was one of the main problems in relation to work for the participants. Peter called it his 'biggest issue' and other participants reported frustration associated with fatigue. Fatigue had caused some participants to change the structure of their work day, especially the incorporation of rest periods. A more substantial change to manage fatigue was done by reducing working hours or days.

*And so now I have issues with my walking, and yeah, with tiredness, and like I can't work for a full day in one go.* (Emily)

Interestingly, the participants seldom recognised or acknowledged cognitive problems, even when their descriptions of problems at work seemed to suggest this as an obvious issue. For example, some participants highlighted word finding and communication issues at work. This seemed

particularly problematic for the participants whose jobs relied on good communication skills with their clients and in meetings.

*I find I do get brain fog, bless it. Especially mid-sentence, when you're talking to a customer, and you've got no idea what you're talking about. I get that from time to time. (Jack)*

*It's frustrating in certain environments, where actually I want to be able to articulate something in some, I know what I mean, and I can't articulate it how I would have been able to before. (Melissa)*

Other cognitive issues experienced in relation to work included issues with poor memory and problems with being able to focus on a task. Sarah reported how she found it difficult to concentrate on a task, especially when an instant response was expected at work.

*Sometimes- if you actually took this piece of paper and put it in front of me and said 'is that right? Read it. Um, give me some feedback.' My brain just can't concentrate on it straight away. (Sarah)*

Changes that the participants reported to help cognitive issues included writing lists to jog their memory, taking more time to complete tasks, having notes made in advance of meetings, or having a supportive colleague to jointly attend important meetings. For one participant these strategies to help manage cognitive issues had not been adequate and led to him giving up that particular work.

*And sort of was in that role for about a year before I started really having that effect from the blurred vision, and translation issues. And then I eventually, I chose to be made redundant, at that point. (Frank)*

A further catalyst for work changes was a perceived loss of enjoyment and dissatisfaction in work. Satisfaction within work seemed to be influenced by being valued and respected, having purpose and routine and being able to perform to an expected capacity. A resounding benefit and also a requirement of feeling that work was worth pursuing and that the difficulties were worth addressing

was the enjoyment participants got from working, and also a love for their work. Work stimulated the participants and helped create a sense of happiness in their lives, even if working was a challenge and harder than it used to be because of their MS.

*Do I really actually genuinely love my work here? Yes I do. (Jack)*

Indeed, the purpose of work helped prevent some participants from focusing solely on their health issues; some believed this prevented their health from deteriorating.

*I think if you lose purpose, then you know, you'll start to go downhill. (Peter)*

Participants who felt undervalued or disrespected, often because of issues related to their MS and misunderstandings about this from their employers, had become dissatisfied with their work. This had led to them wanting to make changes, and for some, wanting new employment completely. This is well illustrated by the following two extracts from Susan's interview. Susan had mobility issues and so she felt unable to perform to her own expectations in her current role. Her boss had suggested other alternatives, but Susan felt this would make her feel undervalued as the alternative roles did not require her to use her key work skills. She wanted a job that gave her a purpose that she was satisfied with; she did not want to be paid to feel like a spare part.

*I think when I feel that I'm not – you know, if I'm just going to be a hole in the wall, not a hole in the wall, but you know, just like a pillar in the corner or something, then I don't want to be that. I don't particularly want to be paid to hold up a wall! (Susan)*

This had driven her to look for new work. In particular she sought a job that involved less walking but in which she felt more satisfied that she could perform at a high level.

*I want a job where I feel like I'm doing my hundred percent, whereas at the moment I know I could do more, but I can't physically do more. (Susan)*

## Influences

In addition to the catalysts for change, a number of factors influenced the participants' ability to make changes. These factors were associated with the process of disclosure of their condition, their own attitudes, work role flexibility, the knowledge and understanding of themselves and others, and their self-awareness of their changing capacity to work.

Participants had a range of experiences around disclosing their diagnosis of MS to their employers and colleagues, and how it influenced work changes. Some participants had found that disclosure had helped them to make work changes and better manage their MS. For others, the experience of disclosure had led to them feeling a loss of control when their employer had made work changing decisions on their behalf.

The disclosure process was often a challenging time for the participants and all participants acknowledged that the process was very individual. Participants voiced how they had wanted to have control over when they chose to disclose their diagnosis. Several participants shared their diagnosis to those at work because they felt it was important to be honest and truthful and in doing so had maintained control over the disclosure process. Other participants had less control as they felt forced to disclose their diagnosis due to having extended sick leave or because their disability had become quite obvious. Further, participants reported feeling forced to disclose at a point when they felt unable to perform their work role at an expected or satisfactory level.

*Well it was in my one-on-one. I said 'Look, I'm just really struggling, really struggling at the moment, just trying to get my head around, you know'. I said 'Doesn't seem right, it's stuff that I could do before,' I said, 'it's probably the MS that's – ' and she [his boss] went 'What? Are you sure?'. (Frank)*

There were a variety of elements that were associated with the disclosure process. Timing of disclosure was a critical part in the experience for the participants. Participants described how they needed to transition through the grief of the diagnosis and get their head around it before they were

ready for disclosure at work and, even then, still found the process of disclosure challenging. One participant had however disclosed her condition to her employer at the point of diagnosis because of the severity of her MS. She felt that she had no control over the choice to disclose as she needed to take time off work and her symptoms were very obvious. She reflected that she had not come to terms with the diagnosis at that time, and that early disclosure had given her employer a reason to judge her differently. She feared that it was because of her disclosure, that her employer had made choices for her in how she would continue working. In a more recent job, she had chosen not to disclose and felt more in control of the changes she made at work and in the management of her MS as a result.

*Because I did then feel that they had – because I hadn't come to grips with it, I felt that they then knew too much too soon. Whereas by the time I came down here, can't say I was still to grips with it, can't say I still am yet. But at least I felt – I knew what I was dealing with.*

*Whereas then I didn't. (Melissa)*

As in Melissa's case, one of the main fears for most participants was around being judged or treated differently after disclosing their MS. They did not want others to pity them or assume their life was a tragedy as a result, and they certainly did not want to make a fuss when needing to make changes to facilitate work. The participants also voiced how they had needed to trust that their employers and colleagues would be supportive before they felt sufficiently comfortable to disclose their condition.

Some participants had found that their employers had made inappropriate choices for them concerning what they were capable of at work since they disclosed their diagnosis. This loss of control made it harder for participants to accept the proposed changes and it also led to the participants feeling undervalued.

*I talked to my boss and said 'Look, it's just getting too much walking,' and so she kind of shoved me in one little area. Which is fine, and she's trying to help me not walk so much, but, it's also making me feel like she's put me in a little box. And that she doesn't – it kind of made you feel like you weren't worth anything how she's trying to help. She didn't talk to me, she just kind of said 'oh we'll keep you here, cause there's not as much walking.'*

*(Susan)*

Disclosure was not essential for the participants to make work changes. Both Melissa and Kate had made successful changes within their work without disclosing their MS diagnoses. Instead of sharing their diagnosis, they had felt more comfortable telling people that they had something wrong without explaining that it was specifically due to MS. Kate, who was a teacher, had told children at school that her leg did not work, when they asked her what was wrong. Melissa explained that she needed to tell people enough at work so they could understand her needs and the changes she made, but without giving the reason for these issues. There were times, however, when she obviously wished she felt able to explain more to those at work.

*But I tell them enough that I feel – they know that my – one of them laughed, because she thinks I'm as blind as a bat, because I can't read things on the screen anyway. So I had to explain about my glasses and things, so that's fine. But there's times that I wish I could explain a bit better, as to why actually I can't see certain bits, and why I can't do certain things. (Melissa)*

A more substantial change made by some participants was to find new work. This process was also fraught with challenges, especially when trying to decide when and how to disclose their diagnosis. Some had originally chosen to disclose on their application forms, but reported that they perceived this had affected their applications because they had only received interest in an application for work when they did not state their diagnosis on the application form and had instead chosen to disclose it at interview.

*But I think it's better if they [future employers] can see what you're like, and then you say 'Hey, I've got MS.' Then when they – I don't want to be judged on a piece of paper.*

*(Susan)*

Wendy, like other participants, had felt discriminated against because of her disclosure during the application process for a new job. She had been contacted by the company's spokesperson following her application and interview. Her interpretation of what was said was that she was not offered the job because of her MS.

*Reading between the lines, and having the phone call a couple of days later, ringing me up saying look, you know, they're really sorry they put me through this, but you know, while they can't say, there's an issue with your disability. (Wendy)*

Despite such challenges, the majority of participants had a very positive outlook on life and on how to manage their MS. Participants felt that it was their attitude that helped them to keep going in work and some of them believed that this positive attitude also helped prevent deterioration in their MS.

*So there's things that I can do. But I have to control. My mind. And that's what I have to plan – now, that solid foundation of controlling my mind to live with it, live better with it. For longer. (Jack)*

It was this attitude that gave them a sense of control when coping with MS; it appeared to make the participants extremely independent and ultimately self-reliant. For many, they felt able to address work place issues and changes because of this approach to their lives.

*Well I have this – if it's to be, it's up to me. Yeah. (Sarah)*

Participants who were positive about their work experiences and who believed in being independent appeared to be very determined and often pushed themselves hard to achieve tasks despite their MS. Some shared how they made themselves walk at work despite the effort involved, while others

shared that they would push themselves hard to achieve tasks at work. This had allowed them to feel like they were maintaining control and not taking the easy option despite the challenges of their MS.

*And so you put a hundred – you probably try and work – put more pressure on yourself, than you would if you didn't have MS. Cause you think 'Well I have to look like I'm working at a hundred and ten percent,' or whatever. Even though I have MS. So I think you put more pressure on yourself to be better, or to do more. (Susan)*

Positive experiences and reflections of previous changes seemed to influence the participants' attitude towards future changes. Melissa had taken part in a fatigue management course which had led to her making changes in her home life. The positive consequences of these changes had led to her being more open and proactive in making changes in work. Frank had struggled to accept the need to make work changes in the past, but had more recently recognised the positive benefits of these changes to him physically and mentally. Thus, by being aware of the positive benefits of change, the participants were more open to further changes in the future.

Two participants recognised that they had reprioritised their work-life balance, changing their attitude to work, which had led to them being more accepting of work based changes. For example, to help manage her MS and create a better home life with her family, Melissa had been more open to making changes in her work. In addition, many of the participants had completely changed their thinking or outlook to get to grips with the issues they were experiencing and the need to make work changes.

*So he [neurologist] said it's just a head thing, and getting your head around it differently, so it's not you can't do something, it's actually how you manage it. (Sarah)*

In addition to the disclosure process and the participants' attitudes, work changes were also influenced by the flexibility within the participants' work roles and their physical work environments.

This aided some participants to take control and make their own choices about what changes would help them at work. For others the nature of their work and the work environment made it harder for them to take control of the changes required to meet their evolving needs and this was a challenge.

Participants who felt they had flexibility in their role to structure and manage their days and workloads, felt that this facilitated them to take control of the changes required at work. Work role flexibility allowed participants to take more rest breaks and structure their day to help manage MS issues. Jack was able to work from home when he was struggling with fatigue and Susan completed walking-based tasks in the mornings and a desk-based activity in the afternoons when walking was harder. Other participants made use of this flexibility to take unplanned time off when their MS symptoms were bad.

*And it's again, it's unwritten, but if I just send my boss an emailed message going 'Having a really bad day, need to work from home,' I know he'll be like 'Okay.' I can't ask for better support than that, right. (Jack)*

Some work roles did not allow as much flexibility and hence some participants had less control over work changes, particularly in roles where the participants provided a service to others. One participant was a nurse in a busy ward, and when her mobility began to deteriorate, she needed to look for alternate work as there was very little flexibility within her nursing role to allow her to make changes. Another participant, a lecturer at a tertiary institution, found it hard to take breaks to manage her fatigue because of the teaching timetable and the expectation of students that she would be available to meet with them at any time of the day.

Work roles that involved travel, either locally on a daily basis or longer distances of travel was challenging for participants, often due to the fatigue they experienced. Some participants had the flexibility in their roles to choose not to travel, while others had had to change their jobs, as travel was a vital part of their previous role. Frank drove for his work on a daily basis, and questioned on

some days whether it was safe for him to drive due to his fatigue. He had sought support and his employer had gained some supplementary funding so Frank could work shorter days.

*And that's when you get to the end of the day, on the last job, at four o'clock, and you're going 'Mm, should I be driving? Really?' You know, so it's definitely one thing [driving] that I found very difficult. (Frank)*

In connection with their work role, for some participants the physical work environment restricted what changes they could make. The environment was also sometimes the catalyst for change, in particular when associated with MS issues such as reduced mobility and balance. A participant who worked in a factory environment had decided to change jobs when he was struggling to walk and felt it unsafe to continue working in an environment that could not be adapted to his needs. Emily had also encountered difficulties in her work environment due to her mobility issues with going up and down the stairs. This had caused her to question her ability to continue working. Fortunately however, for unrelated reasons, her company had moved to an office with a lift which had resolved her work environment issues.

*Like when we had the building which had a flight of stairs, and no lift, I was starting to think 'I think I'm going to have to give it up,' just because of the stairs, basically. Because I was finding that so, so hard. (Emily)*

The participants' knowledge and understanding of MS influenced them making work changes. A number of the participants felt that it was essential for them to come to terms with their diagnosis and have a good understanding of MS before making any work changes. Indeed, two participants who had made changes soon after their diagnosis, had regretted these decisions later on. They believed they would have made better choices if they had waited until they learnt more about MS and would give this advice to others.

*I'd get them to think really carefully about it and find out more about MS first. (Wendy)*

Many of the participants were unaware of support services that could assist and guide them at work. They had often made changes at work without consultation or support from external agencies. For some this had led to successful changes, while others felt in hindsight that if they had sought support earlier they may have made different and more appropriate changes in their work. One participant was aware that there were work support services available to her, but appeared sceptical of the difference they might be able to make.

*I don't know a whole lot about them [vocational support services]. And I'm not sure how helpful they could actually be. (Susan)*

In comparison, another participant had sought support, and had found the process extremely helpful while he established himself within a new work role. Through this support, he had been also able to access specialised funding to support some of the changes he needed to make at work.

The knowledge and understanding of others also influenced work changes. Some participants identified how they had been given advice which conflicted with their own beliefs on whether they should keep working. They had read or been told (for example, by health professionals) that they should not continue working because of their MS. However they all kept on working as their own beliefs and often those of their families, was that it was important to keep working.

*I'd tell him [Doctor] to bugger off. Because I think, if I went to that period of not having work ... And I sort of think that physically, I'd give up, a bit. And keeping working, keeping me – you know, monthly on a – on a monthly cycle of goals, and targets, everything like that, keeps me going, keeps me walking, keeps me going. (Jack)*

Employers often lacked knowledge and understanding of MS, which created challenges for some of the participants. These employers wrongly assumed that an MS diagnosis meant the participant would be unable to continue working, or they tried to make decisions for the participants on what changes they imagined were required to allow the employee to keep working. In contrast,

employers who had sought to be educated about MS to increase their understanding were better able to support their employees, and the participants recognised and appreciated this support. This enabled the participants to maintain control on work changes with the support of their employers.

*And when [MS Nurse] explained it to them [employer], that you know, '[Sarah] might have to have- like her timetable might be – have to look at to have breaks after lunch or something like that... they got me a trolley to move things. (Sarah)*

Even if an employer demonstrated understanding shortly after disclosure, some participants found that they quickly forgot and could have unrealistic expectations. Even Sarah's employer, who had understood about her issues with fatigue, had recently asked Sarah to produce an impossibly large volume of assessment documentation, and to cancel her holiday to do so. The participants felt that employers needed to maintain good knowledge and understanding of them as employees (with MS), so they could appropriately provide ongoing support as changes occurred.

However, participants found that it was often hard for their employers and colleagues to really understand and appreciate the impact of their MS symptoms on their ability to perform at work. This was particularly the case for less visible symptoms such as fatigue and cognitive issues, which the participants thought made it challenging for employers and colleagues to make sufficient allowances and to support changes to facilitate work.

*I don't think they [employer and colleagues] really understood what MS was. It's like I still don't think a lot of people here understand it, because they say you know, like your – you know, if I say that I'm tired or feeling fatigued, they say 'Oh, my we're all tired.' So it's because you look fine. (Sarah)*

The participants' awareness and acceptance of their evolving capabilities at work also influenced the change process. Participants who were better at recognising and accepting their changing capacity appeared to find the change process easier than those who did not. Factors that contributed to the participants' acceptance of their capabilities included acceptance of MS, their ability to cope with

the uncertainty of a progressive condition, awareness of their changing capacity to perform at work, and their self-identity.

As outlined in the section on challenge, the participants found it challenging to accept their MS, changing symptoms and the uncertainty of living with a progressive condition. Many of them struggled to recognise and accept their changing ability at work because they were still coming to terms with their diagnosis. Frank struggled to accept a decline in his condition and this made it hard for him to accept that the problems he was facing at work were related to this recent decline.

*Funny enough, for me, I just wasn't sure what was going on. So I wasn't sure how to address it, what to do with it, you know. Cause it was sort of like 'Well, this doesn't seem right, I'm not coping with this. (Frank)*

Nearly all of the participants felt a need to prove themselves at work to their employers and colleagues, as they did not want to be seen as being unable to perform due to their MS. This drive to perform at a high level made it hard for the participants to accept that their capacity for work might have changed.

*So then I had to go to my doctor, and she wanted to put me off- I've got a very supportive doctor. Whatever I say, she would be there, so she said 'I want you to go off totally.' And I said 'I can't, I've got to write this document, I've got to teach, there's no one else.'*

*(Susan)*

Participants also struggled to recognise and accept their changing capacity because this made some of them believe that they had lost control of their lives because of their MS. This led to them trying to work harder, only to realise with disappointment that they could not maintain performance at that level.

*Personal thing myself. Personal expectation of being able to do more. I – yeah, no, it's very much I expect to be able to do a lot more. And I can't. (Melissa)*

For some participants, self-identity was strongly connected to their profession and work. Many of them had been extremely driven and committed to their careers. This made it hard for them to accept their changing capacity, as they feared making changes at work or changing their career would lead to a loss of identity. Susan acknowledged that she had defined herself by her job but now realised that she needed to find a new identity as her capacity to work was changing.

*I've always been such a hard worker, and I've always defined myself by my work. It's just been since my MS changed that I've had to change the way I've defined myself. (Susan)*

Participants who were good at recognising their work capacity and were able to match this to an appropriate work role seemed more accepting of change. Some participants had the foresight to be able to recognise the benefits they would experience from the change, which aided them in making changes. Indeed, two participants had been pre-emptive in making changes, as they recognised the need to change to ensure a better work-life balance, to help reduce financial pressure and to help self-manage their MS.

## **4.6 Consequence of change**

Once the participants had made changes at work, they experienced beneficial consequences but also some demands associated with the changes. Benefits included improvements in their MS symptoms, work-life balance, and well-being as well as more pleasurable productivity in their work. The participants were also challenged by the demands associated with changes. Participants found that it took time to accept the changes and they were hard to maintain the changes. The application of change impacted others and was often an emotional process for the participants.

### **Benefits**

There was a variety of benefits experienced from making work changes, often leading to the participants having an increased sense of control over their lives and their MS. These positive

benefits created an accompanying positive belief in change, and often enabled the participants to make further changes at work.

A significant benefit of work changes was improved MS symptoms, in particular symptoms that had been a catalyst for change. Most of the participants felt that increased work stress was due to an increase in their symptoms combined with an associated change in work capacity. Stress led to a worsening of symptoms and thus a vicious cycle occurred.

*I'd gone from being somebody who took every step as a challenge, and revelled in that really, I needed stress to work, to someone who couldn't actually cope with the stress at all.*

*(Wendy)*

Making work changes helped reduce stress and improved MS symptoms for many of the participants. In particular, nearly all the participants had experienced an improvement in their fatigue since making work changes.

In addition to improved stress and fatigue, some participants believed that they had improved physically since making work changes. At one point, Frank had been made redundant and while he was not working had found that his mobility had deteriorated. He made the decision to find new work which had led to improvements in his mobility. Other participants had made work changes to allow them to continue working as they believed work helped them stay physically well.

*It was sort of at that point [after being made redundant], I sort of went downhill quite quickly with it, with the MS, feeling really physical, until I sort of just give it – actually, the best way to manage it [MS] is by working, or physically getting out there and doing something. I may not be able to do what I could do before. But I can still do something. (Frank)*

For many of the participants an improved work-life balance was another benefit of work changes. For some of them, this had been one of the reasons for change, and for others it was an incidental benefit. Prior to change, participants had found that work often left them feeling exhausted, which

impacted on their life outside of work. Improvements in work-life balance had allowed the participants to spend more quality time with their family and friends, to do more pleasurable activities and also to contribute more to tasks at home. For participants with children, this benefit of change was extremely important.

*I can enjoy my time with my family more because, you know, physically I'm better.*

*(Frank)*

Participants who recognised the benefits of an improved work-life balance re-prioritised their lives and made home life more of a priority. This led to them making more work changes so they could experience on-going benefits.

*It's a different mentality for me of going work to live, not live to work. So it's that, it's a means to an ends. (Melissa)*

Improved MS symptoms and the associated sense of being in better control of their MS, and also an improved work-life balance, led to many of the participants having a better sense of well-being overall. In addition, many of them strongly believed that being able to work helped them to stay mentally well. They also strongly believed that by continuing to work they stopped themselves going 'downhill' due to their MS. Some felt that work had helped to prevent them from becoming negative and caught up in their own thoughts and problems.

*Cause I know that if I stopped working, that I'd probably go backwards again. And it's kind of keeping me going, even though it is a huge push... to go to work. (Emily)*

A further benefit of change for the participants was rediscovering a sense of pleasurable productivity, a feeling of joy and satisfaction in their work. Kate for example, had changed from being a classroom teacher to a teacher who supported children in reading, which meant she needed to walk less at work. This change had helped her regain her joy for work, which she acknowledged that she needed from work.

*I really enjoy my job and I need that, you know, stimulation, and – yeah, I love going to work, so happy days, you know. (Kate)*

## **Demands**

The participants experienced not only benefits, but also demands because of the changes they made in their workplace, with these demands affecting both themselves and others. A reoccurring demand was acceptance of the work changes. Participants found it was hard to accept work changes, even after making them and this was an ongoing challenge for them. Susan had started using a scooter to help her commute to work but found the adjustment hard as she felt the scooter drew attention to her. Acceptance of the scooter forced Susan to acknowledge that her capacity at work had altered and her MS had progressed.

*I kind of feel a bit conspicuous with my scooter, so I do – I do use it more, but I still don't like – I still haven't got over the fact of – feel like people are staring at you all the time. But that's just something I'll just have to deal with, I think. (Susan)*

Susan and many of the other participants took time to accept the changes once they were made. The length of time required varied, with some participants only needing a few months while others indicated it had taken several years to reach acceptance.

*It probably took about three or four months to really go 'Look, I know I can't do what I did before.' (Frank)*

Some of the participants, who were still working for the same employer but who had had to make a dramatic change in their work role or even a demotion within their work, found that accepting this change was very challenging. Many of them struggled to accept their new role as it left them feeling less valued and respected within their work. This led to reduced work satisfaction and enjoyment and had become a catalyst for them to consider looking for a new job completely.

*Like because they [employer] said 'No, you have to go down two levels [demotion], and do this, that, 'and they treated me a weeny bit – like I'm kind of torn, like they let me stay working, they let me have a job, but, they still treated me like – a bit like 'Oh, you're just a support person now, you don't have a brain, you can't do anything, you can't make any decisions,'.* (Emily)

Another demand of work changes was in maintaining the changes. This was particularly the case when participants had made relatively simple changes to their work routines or to the structure of their work day. It was very easy for them to revert back to old habits without necessarily noticing when this happened – only recognising that they had done this when they became aware of their symptoms or capacity to work altering again. In order to manage his pain levels which were associated with stress and fatigue, Jack had tried not looking at work emails when he was at home. His wife had recently pointed out to him that he had started to do this again and this was associated with him complaining of more pain.

*So I've actually- I've slipped back into it over the last couple of weeks, but I actually made a conscious effort to not do that.* (Jack)

While this was not an issue for the participants who had found new work, it was definitely an issue for those participants who had stepped down from their previous position within the same company. Wendy had gone from being the branch manager to senior accounts manager. With this change she struggled to let go of her old position, and she also found that her colleagues and customers still turned to her to complete tasks which were part of her old role.

*I'd be quite happy to move aside, and let him [a more junior employee] do it. But at the moment, no one else wants anybody [else] from the company to deal with them.*

*(Wendy)*

A demanding consequence of change for many of the participants was the increased impact it had on others at work. Some participants needed to delegate more tasks to their colleagues and even ask colleagues to complete some of their work role. Not being able to fulfil key components of their job such as travelling, and also changing their work hours seemed to impact on others at work the most. Many of the participants believed this was difficult and frustrating for their colleagues and employers.

*I know it's incredibly frustrating for them [colleagues], and for the branch manager ... Yeah, the fact that I don't work Wednesdays, and that I don't travel anymore, while they say it's okay, I know that a lot of the times it's not. (Wendy)*

Some work changes had led to the participants having reduced contact with their colleagues. Changes such as reducing work hours or days, choosing not to attend team meetings or social occasions due to restricted mobility, and not working within the same role had led to an altered team dynamic. Some, but not all, participants were bothered by this loss of social contact at work and most recognised that this was often an issue for their colleagues.

*Yeah – well, they keep saying... They keep saying 'Oh my god, we don't see you,' etcetera. But you know, it doesn't worry me. But they feel I'm missing out cause I'm not part of the team. (Sarah)*

One of the most demanding consequences of work changes for the participants was that they found these changes emotionally challenging and also upsetting at times. It was hard for them to emotionally and mentally accept changes. This was more apparent for the participants who had made substantial changes such as stepping down from a more senior role or changing their career.

*It was nice that my work kept me on... but it was hard, emotionally and mentally for me to have to like give up all my powerful job and titles, and everything that I was doing, and have to just take a step- two steps back[wards]. (Emily)*

Some participants felt that their self-worth in relation to work altered after they had made changes. This seemed to be more an issue for participants who felt as though they had lost control over some of the changes that were made at work. Susan's employer had facilitated her to take on an alternate work role, but this had led to Susan feeling worthless, as though she was not contributing.

*So that does make your self-worth go down. Because you don't – I'd like to feel like I'm at least contributing. (Susan)*

#### **4.7 Results summary**

This thesis aimed to explore the work experiences of people with MS. The study participants shared their experiences, and it was clear from their interviews that many factors created challenges for them. The participants' stories illustrated that work changes were inevitable at some point and for many of them, such changes were challenging. All the participants had distinctly different work change journeys, but there were many common themes that linked their experiences together. The first theme of *'Challenge'* ran throughout the narrative and was related to the MS diagnosis, its unpredictable progressive disease course, and the acceptance of it and the subsequent work changes required. A second theme was *'Choice and control'* where the participants took control of their MS and lives by being actively involved in choosing the work changes needed. The *'Preparation for change'* theme illustrated the catalysts and influences leading to work changes, while the *'Consequence of change'* theme explored not only the benefits of change, but also the demands imposed on the participants and others because of the work changes. This results section has identified some of the work issues for people with MS, in particular issues with making work changes. These will be discussed in the next chapter, as this increased knowledge may help to contribute towards better support for people with MS who are working and facing similar issues.

## **Chapter 5 Discussion**

### **5.1 Research overview**

This IPA study explored the work experiences of people with MS to gain a better understanding of what it was like to work while living with a progressive and somewhat unpredictable neurological condition. The aim was to shed light on the issues the participants experienced at work and to find out what would be helpful, thereby perhaps indicating ways that clinicians could best support their clients to continue working. The main issues for the participants in this study were the experiences of making work changes. This was closely connected with the themes of '*challenge*' and '*choice and control*' that ran throughout the participants' stories. All the participants had experienced a variety of challenges since developing MS, many of which were directly connected to work and making work based changes. The participants strongly preferred to be in the position of making their own choices and being in control of changes in their workplace, particularly as they already faced the uncertainty of living with an unpredictable and progressive condition.

There were two further themes in relation to the journey of change. The first was '*preparation for change*' which encompassed the catalysts that triggered changes and the influences affecting the change process. The second was the '*consequence of change*', which identified both the benefits and demands on the participants resulting from making work changes.

The findings from this research has provided additional insight into the area of employment for people with MS, compared to the focus of previous research that has focussed on factors that are associated with unemployment. This previous research has largely entailed quantitative studies using questionnaires and surveys, which have provided a descriptive and partly predictive account for the association between MS-related or contextual factors and employment status, with little qualitative data on the lived experiences of people with MS. This thesis, perhaps for the first time, has revealed the extent to which experiences of change feature in people's stories of work after a

diagnosis of MS. These changes feature in people's workplace experiences after MS even when employment status has not changed, illustrating how management of work after MS is not just about whether people do or do not have employment.

## **5.2 Making work changes**

This study has identified some novel areas of interest, around the experiences of making work changes, including the influence of accepting both an MS diagnosis and an altered capacity for work. It also illustrated how a person's attitude to life, their MS diagnosis and their work can have a significant impact on their response to work changes. Evident throughout the whole experience of making work changes, was the previously unexplored theme of the need for participants to make their own choices and maintain control. Participants in this study all identified the importance of their work, but shared the challenges and demands they faced, and factors that influenced their ability to make successful work changes to enable them to keep working. This is supported by another qualitative study with academic staff with MS at Canadian universities (Crooks et al., 2009), which highlighted that negotiating MS while working is a complex process that necessitates the adoption of changes so that work can continue. It seems apparent therefore that people with MS have to deal with unanticipated and not always welcome challenges and changes in regard to work. It is having the knowledge and decision-making ability to identify changes and strategies, to request and enact them and to see them through, that are essential for success, or the feeling of success at work.

MS is frequently diagnosed when people are in the prime of their lives, progressing along a career pathway, raising a family and productively contributing to society. They have plans and aspirations for the future and a diagnosis of MS creates an immediate threat in the direction of their lives. They are faced with the need to accept and come to terms with the diagnosis, and to understand the potential impacts it might have on their lives. This was identified by the participants in this study, who found it challenging living with MS and in their journey of making work changes. Like

participants in an earlier qualitative study of unemployed people with MS in the USA (O'Day, 1998), many of the participants in this thesis shared how they struggled with the variability and unpredictability of their MS symptoms and how this challenged them when considering changes they needed to make. Although for some there was a pattern to the variability of their disease symptoms, for many participants this was extremely unpredictable and therefore had been hard for them to plan when making decisions about changes.

Participants in this study also experienced a variety of emotions associated with their diagnosis, and also their disease progression. Many of them had struggled to accept their diagnosis and experienced grief on being diagnosed. Even where participants had come to terms with their diagnosis, they had experienced similar issues around acceptance and grief each time their condition progressed. The issues around grief and acceptance of MS within the previous literature have been inconclusive. A literature review of 72 studies found limited evidence for a pattern in relation to acceptance and adjustment in people with MS (Dennison, Moss-Morris, & Chalder, 2009). While more recently, studies from Australia and Europe have found that acceptance is related to better adjustment to MS, quality of life and successful life changes (Pakenham & Fleming, 2011; Van Damme, De Waegeneer, & Debruyne, 2016). These two recent studies support the experiences of people in this study; that those who expressed issues with acceptance, also struggled to make work changes.

The challenges the participants in this study shared around acceptance of their condition and changing capacity, and the emotional journey they experienced definitely impacted on their work and ability to make work changes. If people with MS are to address these challenges and continue working, then they need support to develop coping strategies (Crooks et al., 2011). This current study has also highlighted the importance of people with MS having support to develop strategies and make work changes.

Indeed, participants in this study were motivated to make their own choices and take control of the changes they made at work (even if this did not always occur because changes were made by their employer). A previous qualitative study of 14 people who worked variable hours in both paid and unpaid roles (Yorkston et al., 2003) also found it was important for their participants to make their own decisions and maintain control over those decisions, because this became a source of strength for them. This supports the findings of this study, in that by making their own choices about how they lived their lives now that they had MS, participants felt they had regained a sense of control. Some participants felt that others, employers in particular, had made choices for them about which changes would be made at work. As in Yorkston et al.'s study (2003), participants in this study found it frustrating and upsetting when others made decisions about work. They felt they had lost control, not just at work, but of their lives in general. It also made them resistant to the changes and many of them struggled to adjust to the new work changes.

A systematic review of the literature investigating adjustment in people with MS found that people who had a higher sense of control and self-efficacy were better adjusted to living with MS and making adaptations in their lives (Dennison et al., 2009). Similarly, participants in this study found that regaining control helped provided an inner strength and a more positive outlook. Feeling positive about change and appreciating the benefits of change, increased the sense of control experienced by the participants and this helped them to continue to make appropriate work changes. Together, the current study and the previous studies begin to indicate the importance of enabling people with MS to maintain a sense of control over their lives.

This study supports other research on the challenges that people with MS face with workplace issues, the challenges of coping with and making workplace changes and also how this relates to their acceptance of a diagnosis of MS. The study in particular has illustrated, through participants' stories, the emotional experiences connected to these challenges and changes.

### 5.3 Catalysts for work change

Previous research has not specifically investigated how MS symptoms lead to work changes but has identified an association between MS symptoms and an altered employment status. Participants in this study were triggered to make work changes by a number of MS symptom catalysts, including fatigue and physical problems. Although less acknowledged by the participants, cognitive issues also appeared to lead to work changes. In addition to MS symptoms, losses of enjoyment or satisfaction within work were further catalysts for workplace changes for participants in this study.

One of the main catalysts that made participants in the current study make work changes was fatigue. Fatigue has been identified as a principal predictor for employment status change in a large body of literature using both quantitative and qualitative methodologies (Glad et al., 2011; Glanz et al., 2012; Johnson et al., 2004; Julian et al., 2008; Krause et al., 2013; Moore et al., 2013; Morse et al., 2013; O'Connor et al., 2005; O'Day, 1998; Simmons et al., 2010; M. M. Smith & Arnett, 2005; Yorkston et al., 2003), and this supports the participants stories in this study, where fatigued was expressed as being one of their main problems causing them to change the structure of their work day, needing to take rest breaks and reducing their work hours.

Participants in this study expressed how fatigue was often associated with other MS symptoms such as reduced mobility and cognitive function. They explained how the effort of walking with an altered gait or having to focus on a demanding task caused them to become more fatigued, or vice versa. That when they were fatigued, they became aware of a further decline in their mobility or cognition. This supports other research, for example a qualitative study of 16 people with MS that investigated the costs and benefits of work (Johnson et al., 2004), where fatigue was closely associated with cognitive changes.

It was often the invisibility of fatigue that was the real issue for the participants in this study, because this made it difficult for their work colleagues and employers to understand how fatigue affected them and that they needed to make changes. Some of the participants in this study hinted

at tension between themselves and colleagues or employers at work because of the invisibility of fatigue and these issues are also borne out in other qualitative literature (Crooks et al., 2009; Johnson et al., 2004; O'Day, 1998).

Given the results of this study and previous research, it is not therefore unreasonable to expect the majority of people with MS to experience issues at work in relation to fatigue. It would seem imperative that people with MS recognise the impact fatigue can have on their work and learn ways to manage their fatigue in the hope of encountering fewer work issues.

Mobility and balance changes were also catalysts for work changes in this study. Mobility changes and balance problems have been found to be associated with a change in employment status in previous cross-sectional studies (Benedict et al., 2014; Bishop et al., 2013; Julian et al., 2008; Krause et al., 2013; Messmer Uccelli et al., 2009; Moore et al., 2013; O'Connor et al., 2005; Phillips & Stuifbergen, 2006; Salter et al., 2010; Simmons et al., 2010; M. M. Smith & Arnett, 2005; Strober et al., 2012).

Like a previous study looking at the factors that contribute to employment status change (Bishop et al., 2013), in this study, mobility restrictions and the use of a mobility device had caused participants to reduce their employment or change their job completely. Even early on in their MS when they had minimal changes in their mobility, participants had experienced issues at work that led to them making changes. Similarly, Salter and colleagues (2010) in a retrospective review of over 8000 questionnaires found the greatest proportional increase in unemployment occurred in ambulatory clients with mild loss of mobility.

It appears that both mobility and balance changes are likely to impact on work for people with MS. It would seem useful therefore that where possible people with MS seek treatment to improve these problems, or make use of aids to alleviate the impact of mobility changes on work or otherwise consider how to adapt their work to accommodate for mobility and balance issues. If this is not

possible, they will need to be supported to find more suitable work that could accommodate limitations in mobility. Clinicians need to be prepared to explore the consequences of early mobility issues, as mild changes in mobility appear to have a large impact on work.

Based on the participants' descriptions of work problems (issues with recall, planning and concentration) in this study, it would appear that many of them may have been experiencing cognitive issues and this had led to them making work changes. However, they seldom recognised or acknowledged these cognitive issues. This is supported by previous research that around 65% of people with MS have cognitive changes but these are often poorly recognised or reported (Rumrill Jr, 2009), and people tend not to report them in the early stages of disease progression (Glanz et al., 2012; Honarmand et al., 2011; M. M. Smith & Arnett, 2005).

Work problems related to cognitive issues, whether identified as such or not, appeared to be a catalyst for some participants in this study to make work changes. This is in keeping with a wide variety of previous research that found that cognitive issues were associated with a change in employment status (Benedict et al., 2014; Bishop et al., 2013; Johnson et al., 2004; Julian et al., 2008; Krause et al., 2013; Messmer Uccelli et al., 2009; Moore et al., 2013; Morrow et al., 2010; Simmons et al., 2010; Strober et al., 2012; Yorkston et al., 2003). Research in the USA, Europe and Australia found that lower levels of cognitive function, in particular changes in information processing speed, memory and verbal fluency contributed to employment change (Bishop et al., 2013; Krause et al., 2013; Messmer Uccelli et al., 2009; Simmons et al., 2010; Strober et al., 2012) and these were problems identified by the participants in the current study.

Participants in the current study did not appear to understand that problems with word finding or memory are the result of cognitive impairment. However, Melissa's statement that 'I would prefer things to go wrong physically than mentally' would indicate that she understands the concept, but perhaps did not want to recognise it as a problem, possibly due to a fear of cognitive decline.

Previous qualitative studies also support the fact that people with MS find cognitive issues

frightening (Johnson et al., 2004; Yorkston et al., 2003). Other reasons for Melissa's statement and for other participants' responses to the possibility of cognitive issues might be related to how others might judge them (i.e. the stigma of an intellectual impairment) or that cognitive issues are perceived as harder to manage in a work environment (Johnson et al., 2004). It was also interesting to note that many of the current study participants directly associated work issues in relation to cognitive changes more due to fatigue than the cognitive changes themselves, and is similar to findings from previous research (Johnson et al., 2004; Yorkston et al., 2003).

Given the difficulties and reluctance of people with MS to recognise cognitive problems, clinicians therefore need to be able to identify those who may be experiencing cognitive problems. On identification of cognitive problems and work issues, clinicians need to support their clients to make appropriate work changes and help with the fear associated with cognitive problems. Helping people reframe cognitive problems in a non-stigmatising way may also assist people to confront these issues sooner.

A loss of enjoyment and satisfaction within work was also a catalyst for the participants in this study to make work changes. For many participants making changes led to better work-life balance and also an improved sense of well-being. This appears to be one of the first studies to highlight the importance of enjoyment and satisfaction within work for people with MS, although there is limited previous research that has shown an association between employment and quality of life (Chiu et al., 2015; Forbes et al., 2006; Krause et al., 2013; Krokavcova et al., 2012; Krokavcova et al., 2010; Messmer Uccelli et al., 2009; Miller & Dishon, 2006; T. G. Pack et al., 2014; Patti et al., 2007), and this reinforces the stories of the participants in the current study.

Many of the participants in this study experienced a loss of enjoyment in their work when they experienced work issues due to their MS. Job satisfaction has been found to reduce with increasing barriers in the workplace; such as issues with the work environment or role, and physical or cognitive problems (Rumrill Jr, Roessler, Vierstra, Hennessey, & Staples, 2004). Participants in the

current study expressed a variety of these barriers; leading to a loss of enjoyment and satisfaction. Increasing symptoms has been found to be associated with uncertainty for people with MS in their ability to continue working, which can then lead to reduced satisfaction and further uncertainty (T.G. Pack, Roessler, Turner, & Robertson, 2007) and was predictive of job turnover. Perhaps in an effort to help reduce this uncertainty and regain job satisfaction, participants in the current study were keen to make workplace changes. A study to investigate the relationship of MS related issues including employment status and quality of life (Forbes et al., 2006) also found that participants who experienced employment problems reported a lower quality of life. Participants in the current study reported feeling dissatisfied due to issues with performing their work; this is supported by the study by Glanz et al (2012) where reduced work productivity was found to be associated with reduced quality of life.

The improved well-being or quality of life experienced by the participants in this study after making work changes could be due to a variety of factors. Improved MS symptoms and the associated sense of being in better control of their MS, and also an improved work-life balance seemed to contribute to better well-being. However, the most significant contributing factor towards improved well-being was the ability to continue working, along with a sense of the work being sustainable. The work changes that the participants made facilitated them to continue working and they all believed that being able to work contributed to their well-being. Work created a purpose and routine to their lives and stopped them from becoming negative and caught up in their own thoughts and problems due to their MS. This is in agreement with previous research, work is therapeutic – it prevents individuals from dwelling on their MS and helps them have a better life despite living with MS (Johnson et al., 2004). Similarly in another qualitative study, work was found to be a valued life role for individuals with MS, with the desire to continue working being driven by this perceived benefit (Crooks et al., 2009). These factors motivated the current study participants to continue working, even if they needed to make further changes to enable work. The evidence would suggest that even if people with MS have to reduce their hours of work, they still have an increased sense of

satisfaction and quality of life than those not working (Chiu et al., 2015). Therefore the stories of the individuals in this study and other literature indicate that it is important for people with MS to continue working as it helps them to maintain a better quality of life and sense of well-being. People with MS need to recognise that there are benefits beyond the obvious financial one, and that they are important reasons for them to continue working. It must be remembered that work problems can lead to a perceived reduction in quality of life, and so people with MS need to be supported to make appropriate changes to reduce these work problems, and so regain a good quality of life.

#### **5.4 Influences on change**

Participants in this study found that many factors influenced their ability to recognise the need to change, choose what changes to make, and when to make these changes. The findings of previous research looking at the association between disclosure and discrimination, work environment; and employment status corroborates the findings of this study.

Diagnosis disclosure influenced the work changes that were made by the participants in this study. Some of the participants had positive experiences of disclosing their diagnosis. Their disclosure facilitated them to make choices about work changes in consultation with people at work. This had led to successful changes being made and created a sense of control for these participants. For others, the experience of disclosure was more negative, and had led to them feeling that they had lost control if their employer then made work changing decisions on their behalf.

Whether disclosure resulted in a positive or negative outcome, nearly all of the participants shared how they had feared disclosing their diagnosis as they were worried about being judged by others at work, and about the consequences of the disclosure. Unfortunately for some participants their disclosure had led to their employers making poor decisions about their capacity to continue working, often due to a lack of knowledge and understanding about MS. Similar issues have been identified in previous qualitative literature (Johnson et al., 2004; O'Day, 1998; Yorkston et al., 2003),

where employers were reported to have made inaccurate assumptions about their employees' capacity to work, and made decisions to the employees' detriment as a result.

When employers had enforced work changes, participants in the current study felt undervalued and some also felt as though this was a form of discrimination. In fact, research from the USA shows that people with MS frequently feel discriminated against when at work, particularly after making a diagnosis disclosure (Benedict et al., 2014; Johnson et al., 2004; O'Day, 1998; Roessler et al., 2011). Some participants in the current study had experienced discrimination in the form of a demotion or enforced change in their job description when they requested to make a change to help manage their MS. A study from the USA suggests that these forms of discrimination can negatively affect a person's productivity and job satisfaction (Neath, Roessler, McMahon, & Rumrill, 2007), and this was certainly the case for participants in the current study.

Some participants in this study experienced discrimination during the recruitment process when seeking new employment. Some felt this had happened when they disclosed their diagnosis within their application forms, while others reported experience of discrimination after they shared their diagnosis at a job interview. This is similar to a survey conducted by Roessler and colleagues (2011), where 29% of their participants also reported discrimination when applying for new work.

One American study that reviewed 3669 allegations of discrimination, found that it can often be hard to prove when discrimination has occurred, partly due to perceived discrimination not always being the same as actual discrimination (Roessler et al., 2007). It may therefore be difficult to identify and describe evidence to substantiate claims of discrimination. If the experiences of discrimination shared by the participants in this study were proven, then it could be questioned whether the employer had acted within the bounds of current employment law in New Zealand. The New Zealand Human Rights Act (1993) states that employers cannot discriminate when employing an individual with a disability, either at recruitment or within the terms and conditions of employment (Ministry of Justice, 1993). Although hard to prove, some of the participants in this

study possibly could have pursued a discrimination case based on this act. As would likely be the case for people in general, people with MS may not be familiar with employment law and therefore could be unaware of their rights pertaining to work access and opportunity. Equally, the effort and energy required to pursue a discrimination case may simply be too much for individuals already dealing with the additional challenges of living with MS.

It seems apparent, that people with MS could be better supported through the process of diagnosis disclosure at work and previous studies have supported the need for vocational services at the point of disclosure (Neath et al., 2007). People with MS need to be aware that they cannot be forced to disclose and there is no correct time to disclose. Based on this study, people with MS should only disclose at a time when they feel comfortable to do so and this will be different for each individual. Their own acceptance and understanding of MS is likely to influence when they are ready to disclose and they also need to feel that they have a good trusting and supportive relationship with their employer. It would be advantageous for individuals to be able to access support outside of work to talk through the disclosure process, and in some cases this could be extended to support at the time of disclosure with their employer. Indeed, one participant in this study had found it extremely helpful to have the MS outreach nurse attend a meeting with her employers with her to discuss her diagnosis of MS and to talk through the implications of this.

There are different ways to provide support; it may be somewhat intimidating for people with MS to be informed about the possibility of discrimination and their employment rights immediately after diagnosis. It may be more appropriate for health professionals working with people with MS to help identify potential cases of discrimination, and support their clients to understand their rights as an employee at that point.

In this study, the participants' attitudes towards their lives in general, their MS and their work strongly influenced how they coped with making work changes. A previous literature review concluded that being optimistic is related to better mental health, well-being and adjustment in

people with MS (Dennison et al., 2009). In keeping with the findings of that review, the positive outlook of the participants in this study appeared to aid individuals to make changes and continue working despite the challenges they faced because of their MS. Some of the participants also believed that their positive attitude helped prevent deterioration in their MS, and led to a sense of control over living with MS. A previous positive experience of change influenced the participants' attitudes towards, and acceptance of further change.

It appears from the current study that people who have a positive attitude towards life are more accepting and open to making work changes. People with positive attitudes may require minimal support to make work changes, but it is people with a less positive outlook who may need support to help them change their outlook and cope with making work changes.

A survey of a large group of people with MS in Australia (Simmons et al., 2010), identified that 20% of them had left employment because of environmental issues at work. Some jobs allow more flexibility in work role and environment to facilitate work accommodations (Crooks et al., 2009; Johnson et al., 2004; O'Day, 1998). Several participants in the current study shared how a flexible work environment had led to them being able to make work changes. This often meant simple changes such as getting a new desk or chair. Less adaptive environments such as a factory or hospital ward were more problematic, and in some instances had led to the current study participants seeking new work.

Flexibility within the participants work roles in this study aided them to take control and make their own choices about what changes would help them at work. Previous research found factors such as flexible work schedule; increased freedom in planning work schedules; ability to take rest breaks and freedom to take time off work made work easier, and this also appeared to be the case for the participants in this study (Benedict et al., 2014; Crooks, Stone, & Owen, 2011; Johnson et al., 2004; Messmer Uccelli et al., 2009; Yorkston et al., 2003).

In work that has flexibility in work role and environment; small and inexpensive changes can successfully facilitate people with MS to remain at work and can be applied to a variety of work settings (Crooks et al., 2011). Clinicians need to consider this when supporting clients, identifying those who have flexibility in their work roles and environments, and suggesting appropriate changes. For clients who do not have flexibility in their work roles or environments, clinicians may need to provide increased support as the changes required to continue working may be harder to implement and accept.

The participants' awareness and acceptance of their evolving capabilities to work influenced their work changes. Like previous qualitative research, participants in this study who could recognise and accept their changing capabilities found it easier to make work changes (O'Day, 1998; Yorkston et al., 2003). Their acceptance of their capabilities was strongly linked to their acceptance of the diagnosis of MS, their ability to cope with the uncertainty of a progressive condition, and their self-identity.

There appears to be little research that has reviewed how disease acceptance affects the lives of people with MS. Two recent studies, from Australia and Europe, found an association between acceptance and adjustment in people with MS (Pakenham & Fleming, 2011; Van Damme et al., 2016). Van Damme and colleagues (2016) in their study investigating acceptance and quality of life in 117 people with MS using self-reported outcome measures found that it was easier for their participants to be flexible and adjust their life goals if they had accepted their MS. However, this was a cross-sectional study and so the authors were unable to determine if the acceptance aided the flexible life goals or vice versa. In the current study, acceptance was critical in the participants' ability to make successful work changes. This is in keeping with Van Damme et al.'s (2016) study, which described how it took time for people with MS to accept a diagnosis, and often this was only achieved as they gained knowledge and understanding of the condition. Knowledge and support have been shown to improve adaptation and adjustment in people with MS in previous research (Dennison et al., 2009; Ghafari, Fallahi-Khoshknab, Nourozi, & Mohammadi, 2015). Despite some

participants in the current study having had MS for many years, they were only just acknowledging and accepting their diagnosis at the time of this study, often because of facing more limiting symptoms and problems. It was hard for them to recognise their changing capacity for activity and function, and this often led to them being resistant to making changes to accommodate these new needs. Until they were ready to accept their diagnosis and their changing function, they were unable to make appropriate changes, and so continued to live with the struggles of MS. This need to accept their MS diagnosis was an on-going issue for all the participants, as it became apparent that they often needed to re-address their acceptance of their condition after each progression of their MS.

A need to prove themselves at work and also a resistance in accepting a change in their capabilities was linked to the current study participants' determination to maintain a sense of control over their MS and their lives. Being unable to perform at high levels within work left many of the participants feeling as if they had lost control of their lives.

Interestingly, a number of participants in this study struggled to accept their changing work capabilities as they felt strongly that their work contributed to their self-identity. They were resistant to making changes for fear of losing their identity if they could no longer work in the same capacity. This is in contrast to Crooks and colleagues (2009) who suggested that the participants in their study were motivated to change as their identities were linked to their occupations. Crook et al.'s (2009) study differs from this one in that all their participants continued to work within the same role or career, whereas some participants in the current study had needed to seek alternate work or change their profession.

This study would suggest that people with MS need to have a degree of acceptance of their condition, disease progression, and evolving work capabilities if they are to make successful work changes. They need to be supported by all health professionals to gain knowledge and understanding of MS, as this appeared to facilitate acceptance within this study population.

Improved acceptance will not only help people with MS cope better at work, but also cope with the other challenges in their lives because of their MS.

## **5.5 Vocational support and advice**

All the participants in this study strongly believed in the importance of working and all wanted to work despite it becoming more challenging and requiring them to make more changes to aid work. This is supported by a literature review of 89 studies (Sweetland, Riazi, Cano, & Playford, 2007). An obvious benefit of work and one that is often the driving force for people with MS to remain working is the financial benefits (Johnson et al., 2004; Messmer Uccelli et al., 2009; Yorkston et al., 2003). This was cited as a reason to continue working by the participants in the current study. However, this certainly was not the only benefit that kept the participants working. Other benefits included having a meaningful purpose in their lives which created a sense of value and fulfilment that encouraged the participants to continue working. A number of the participants also shared how their work contributed to their self-identify and feelings of self-worth. Past literature has also found that employment helps create a valued life role, contributes to a person's sense of self-identify, improves self-esteem, is important for a sense of well-being and is important for a person's position in society (Crooks et al., 2009; Johnson et al., 2004; Sweetland et al., 2007; Yorkston et al., 2003). As discussed earlier, the enjoyment and satisfaction of working, and the associated improved quality of life were also reasons why the participants in this study continued working. Traditionally, people with MS have received advice that they should give up work as soon as it becomes difficult for them to work and for some, this would be even at the point of diagnosis. This is illustrated by the findings in this study and in previous research (Johnson et al., 2004), where participants described how they had read in literature or been told by a medical professional that they should consider giving up work because of their MS. This appears therefore not to be suitable advice given the importance people with MS place on working and the benefits they experience from working.

In my clinical experience, however, advice given to people with MS by health professionals does now seem to be changing slowly. Certainly in the city where this study was completed, people with MS are now encouraged to keep working for as long as possible. This change in advice is likely to be due to the emerging evidence on the benefits of work, and also be due to a better understanding that physical activity (which could include work activity) does not appear to cause MS to advance more quickly or trigger relapses, as had been previously speculated (Sutherland & Andersen, 2001). Indeed, there appears to be no research into the adverse effects of work on MS progression or relapses, with recent research showing no deleterious effects of physical activity or exercise on MS symptoms or progression (Rietberg, Brooks, Uitdehaag, & Kwakkel, 2005). In fact, a literature review has suggested that exercise may actually have a disease-modifying effect, slowing the progression of MS (Dalgas & Stenager, 2012). Based on this information, it is reasonably safe to suppose that people with MS should be able to continue working without it having a negative effect on their disease, as long as they manage their condition well. One caveat to this statement is that, while no adverse effect has been found to arise from increased physical activity, there is still some evidence suggesting a link between sustained psychological stress and disease progression for people with MS (Gold et al., 2005). It is therefore important that people with MS are supported to minimise work based stresses to help avoid exacerbations and possible progression.

This study and previous literature would suggest that it is important for people with MS to continue working. They are likely to face many challenges while working and will be required to make changes to enable them to continue working. However, the benefits for the individuals with MS, their families and society as a whole, mean that it is essential to support people with MS to remain at work for as long as possible.

To enable people with MS to continue successfully working, they need to be able to access the appropriate support services. It would appear from my experience that these services are currently lacking in New Zealand. Like the participants in the current study and other research (Crooks et al.,

2011; Johnson et al., 2004), people with MS are often left on their own to figure out their work issues. It has been found that people with MS want support to make changes but are often unaware of the available support services (Sweetland et al., 2007). This was certainly the case for many of the participants in this study.

Even if people with MS were aware of the support services available and appropriate referrals were made, it is my belief that this would still not help manage many of the work issues identified in this study. Currently available in New Zealand are a variety of vocational support services, ranging from district health board services that assess work place issues, to non-government organisations which support with searches for new work and funding to make some work adaptations. Unfortunately these services have limited funds and are often oversubscribed meaning that they can only support a client on a single occasion (Workbridge, 2015). This is not suitable for most people with MS as their condition is progressive and they may need ongoing support. The services currently available are very good at supporting clients with suggestions on how to improve their workloads, schedules, and their physical work environments but rarely address the psychological and emotional issues which impact on work. This study has highlighted that if people with MS are to make work changes successfully to aid them to continue working, then they need to address psychological issues, especially around acceptance and grief. Not only do the vocational support services need to provide support and advice on environment and work schedule issues, but they may also need to help support their clients with the many psychological issues of living with a challenging condition, as supported by previous research (Van Damme et al., 2016).

The MS Societies in New Zealand endeavour to support their members with MS to continue working. This is generally by referral on to appropriate vocational support services, as they lack the funds or knowledge to provide these specialised services themselves. Better vocational support services are needed for people with MS. They need to be freely available at all times throughout the individual's working life, from the moment of diagnosis until a point where it is no longer possible for that

person to continue working. As suggested by Johnson and colleagues study (2004) and also supported by the current study, the timing of support is critical. The timing of referral to vocational services needs to take into consideration the readiness of the person with MS to make work changes, and their acceptance of their MS and changing work capacity.

One of the benefits of making work changes for participants in this study were improvements in their MS symptoms, and this encouraged them to consider further work changes that led to ongoing benefits. Research has shown that people prefer to make accommodations that lead to functional improvements in mobility, fatigue and other MS symptoms (Johnson et al., 2004).

Vocational services need to consider this when assisting their clients to ensure sustainable work changes.

Participants in this study were driven to choose and take control of the work changes that they made, as were participants in Johnson and colleagues study (2004). Vocational services need to be mindful of this when supporting clients with MS, and facilitate them to make their own changes, as this will lead to better acceptance of the change. This study and previous research (Sweetland et al., 2007) indicate that vocational services need to provide advice and support around disclosure and possible cases of workplace discrimination to their clients with MS.

A survey of highly paid people with MS from the USA, found that a workplace accommodation service (Vocational team) was marginally successful in supporting people with MS to remain in work (Rumrill Jr, Fraser, & Johnson, 2013). That study found that low impact and low cost changes were most likely to be provided and the most successful. A Cochrane review found no evidence that vocational rehabilitation services are effective in people with MS (Khan, Ng, & Turner-Stokes, 2011). From this evidence, it would appear that the current vocational services offered to people with MS are not addressing their needs, probably due to the complexity of issues influencing employment (Frain et al., 2015; Julian et al., 2008; Khan et al., 2011). Vocational services need to be reviewed and

adapted if they are to be effective, and findings from this study may help support a review of vocational services.

## **5.6 Strengths and limitations of this study**

This study contributes to the small but growing body of knowledge in relation to work for people with MS. When considering the findings from this study, it is important to consider the influence of my dual role as researcher and clinician for participants in this study. This power dynamic could have possibly influenced the way the participants viewed me in the research, the information that they chose to share, and my interpretation of the research. While participants' prior experiences of me as their clinician may have made them more comfortable and willing to volunteer to take part in the study, it could also be argued that participants volunteer for a study in the hope this may lead to them gaining additional support or because they fear reprisal in their care if they do not volunteer (Conneeley, 2002). These motivations may have influenced the type of information shared by participants in the interviews – although no evidence of such influence was immediately obvious in any of the interview transcripts or through my interaction with the study participants.

Instead, at least from my perspective, my clinical role seemed to facilitate a quick rapport with the participants and they appeared to be comfortable in sharing a depth of experiences. However, there were also occasions when participants were not explicit when telling their stories, presumably because they assumed a previous level of knowledge and understanding between themselves and me. This often led to me having to confirm information to ensure an agreed understanding of their experiences was achieved with the context of this study.

A criticism of qualitative studies and particularly those with homogenous samples is that the findings cannot be generalised to a wider population (J. A. Smith et al., 2009). In fact based on the people who volunteered to take part in this study it became a very homogenous sample (i.e. mostly women of a similar age, in professional work roles) and this also needs to be considered when reviewing the

results. Although participants who had stopped work within the last six months could have been included in the study, no one who met this criterion volunteered to take part in the study. This meant that all participants in the final study sample were working, and so these results can only be representative of people who are working and not those who have stopped work. This study also explores only the experiences of people with MS working in professional capacities, as no one from manual labouring occupations volunteered for the study. It is not unreasonable to expect that people in more manual labouring roles have quite different experiences to the participants in this study – perhaps being more vulnerable to changes in physical abilities for instance. Interestingly other studies that have looked at MS and work have also found this a study limitation (Johnson et al., 2004; Moore et al., 2013; Morse et al., 2013).

All participants were recruited from a single MS Society in a metropolitan city in New Zealand. This may mean that the results are not directly transferrable to people from other cities or countries, or to rural settings. Furthermore, recruitment through an organisation like the MS society, where the membership is voluntary may have led to the recruitment of participants who already have a specific approach to the management of their MS and novel experiences.

One of the influences on work changes was the attitude of the participants. It is possible that only people with a positive outlook on life and who felt positively about their MS, volunteered to take part in this study. This may have skewed the interpretation of how participants' attitudes influenced the journey of change. It appeared that all participants were very positive in their attitudes, but the stories they shared indicated that this had altered throughout the course of their living with MS and making work changes. As such the findings of this study may also be relevant to people who do not currently have such a positive outlook.

## 5.7 Recommendations for future research

There is a need for further research into work related issues for people with MS. This study and those that have preceded it have only scratched the surface of the complexity of issues people with MS experience in relation to work. In particular, the limitations of this study suggest that studies that focus on the experiences of those who have stopped work and who work in manual labour type roles would be beneficial. As illustrated in this study, flexibility within work roles facilitated changes that enabled participants to continue working. People in manual labour type roles may have less flexibility within their roles and may also find the physical symptoms of MS have a larger impact on their ability to work, which merits further exploration, and has been suggested by other authors (Frain et al., 2015).

There appears to be no research that has explored the issues of employment for people with MS from an employer's perspective. Employers who have staff with MS could provide an interesting insight into the work issues of their staff. Research into this area might help improve our understanding of issues around perceived discrimination and lack of work accommodations by employers for people with MS.

This study, as in previous research (Crooks et al., 2011), has identified that people with MS would benefit from support to address work related issues, but often do not seek support or are unsure of where to seek support. A study that explores why they do not seek support and what support they would wish to access would guide clinicians to develop acceptable and suitable vocational support services.

The importance of managing change in the workplace evolved as the focus of this study. Research on change management in the workplace from an industrial-organisational psychology perspective (such as has been applied to people facing workplace changes for other reasons) might be of value when considering strategies for how best to help people with MS approach and cope with change in their work lives (e.g. Bordia, Restubog, Jimmieson, & Irmer, 2011; Kirsch, Chelliah, & Parry, 2012;

Tummers, Kruyen, Vijverberg, & Voeselek, 2015). Such research would be likely to provide invaluable information on how to support people with MS make essential changes and improve their lives.

Another area for research from a psychological perspective would be how people's acceptance of their MS diagnosis influences how they cope with the condition. In this study, the participants' acceptance of their diagnosis impacted on their experience of disclosure and their ability to recognise their changing work capabilities. It also strongly influenced their ability to choose appropriate work changes and to accept these changes. Having a better understanding about the acceptance process would allow clinicians to support their clients to reach a point of acceptance more easily. It would also give clinicians an appreciation of how acceptance may impact on their client's ability to manage their MS.

## **5.8 Recommendations for clinical practice**

Based on this study and previous research there are number of recommendations for clinical practice that could improve the working lives of people with MS. Participants in this study strongly believed in the importance of continuing to work despite it often becoming harder to work due to their MS. Other studies have also shown benefits from employment, and so all clinicians working with people with MS should encourage and support their clients to continue working.

Given the complexity of issues and challenges in relation to work experienced by people with MS, all clinicians need to be proactive in exploring these issues at every given opportunity. There is no single time when clients may experience problems, so clinicians need to continually assess for work issues.

This study and previous research has indicated that people with MS can often start experiencing work issues long before overt disability, and so it is critical that clinicians start asking about work issues soon after a client is diagnosed with MS.

From my experience (and in personal communication with health professional colleagues), it appears that clinicians tend to approach the topic of work superficially with their clients, rarely exploring these issues in enough depth to understand the full impact of them for the individual. It needs to become common practice for clinicians to perform an in-depth screen for possible work issues, provide appropriate support and refer on to other services as needed.

In-depth screens should review how clients are coming to terms with their diagnosis and MS progressions as this influences their ability to self-manage their MS, and make appropriate changes. It is also important to address factors such as fatigue, physical problems and cognitive changes that often become the catalysts for work changes. Exploring the flexibility of a client's work environment and role will allow clinicians to identify work issues, and facilitate individuals with MS in making their own work changes.

This study highlighted how a person's acceptance of their diagnosis, their attitude and also the emotional issues in relation to living with MS, influenced their ability to make work changes. From my experience in New Zealand, clients with MS struggle to access publicly funded psychological support to address some of these critical issues. Many people with MS would benefit from accessing psychological services to help them come to terms with and better manage their MS. A previous qualitative study also found that participants felt that they would benefit from psychological support as part of a vocational rehabilitation service (Sweetland et al., 2007). Clinicians and the New Zealand MS societies need to advocate for these services to be widely available to their clients.

All clinicians working with people with MS need to provide education for them on possible problems they may experience at work and how to access support to address these issues. The importance of knowledge and support in helping people with MS adapt to their condition has been found in previous research (Ghafari et al., 2015), and supports the need for an education component to vocational support services. Clinicians need to ensure that their clients are referred to the

appropriate support services in a timely manner, particularly as this and other research (O'Day, 1998) indicates that it is better to intervene before a crisis.

In relation to making work changes, clinicians would benefit from becoming familiar with the principles and models of behaviour change management so that they can facilitate their clients to make work changes. For participants in this study, previous positive experiences associated with making changes enabled them to make further changes. Exploring a client's previous experience of change could help clinicians to promote further change, especially if the client is struggling to accept the proposed changes.

To have true success in enabling people with MS to continue working, they need to be supported by a team of clinicians who can address the complexity of issues experienced in relation to work. To ensure this success, there needs to be clear and open avenues of communication between clinicians so that all work place issues are addressed in a timely and efficient manner. Clinicians need to be aware that unfortunately clients with MS can and do experience discrimination in the work place. Where possible they should support their clients to address these issues, and if needed, refer them to appropriate services if their clients wish to pursue a discrimination case.

In addition to the above recommendations, physiotherapists also need to support their clients to address the physical problems, in particular mobility and balance issues that may be impacting on their client's ability to work. They need to provide interventions which aim to minimise such physical changes. If this is not achievable then physiotherapists need to look at equipment that may reduce the impact of mobility and balance issues. Physiotherapists and occupational therapists also have a vital role to play in assisting their clients to become better managers of their fatigue and therefore reduce the impact of fatigue on their work. Workplace assessments could also address problems related to reduced mobility and fatigue, and assist people with MS to make changes to the work environment and also work role.

Vocational services should support clients with MS to make appropriate work changes. In cases where this is not possible, clients may need support to find more suitable work, given their limitations. Staff working in these services need to be aware of the many challenges clients with MS face, in particular the psychological adjustments required by individuals to come to terms with their diagnosis and accept the need to make changes. As found in this and Sweetland's (2007) study, people with MS are often unaware of the available support services, so it is critical that these services are promoted to MS clients in a timely manner.

## **5.9 Conclusion**

This study explored the work experiences of people with MS. It was hoped that this exploration would help clinicians to better support their clients to continue working. The participants' stories highlighted the issues they experienced in relation to making work changes. They were faced with a variety of challenges due to living with a progressive and unpredictable condition. They sought to take control of the choices they made regarding work changes as this empowered them and they otherwise lacked control over their condition. In their journeys through workplace change, their preparation for change was influenced by many factors. They recognised a range of benefits and demands as a consequence of the changes they made and this influenced their preparation for future change.

The finding of this study supports previous literature that indicated that the relationship between disease-specific, demographic, and contextual factors and employment is complex. It is however, one of the first studies that revealed the complexities of making workplace changes to enable people with MS to continue working. People with MS need to be aware of their changing capacity for work due to their evolving MS symptoms, in particular fatigue, physical problems and cognitive changes. In order to make successful changes, people with MS need to develop acceptance of their condition, and possibly change their outlook on their future lives. They need to realise that there

will be an appropriate time for disclosure at work, and this is different for everyone. However, disclosure is not required for them to make successful changes.

Based on this study and previous research, people with MS need to be aware of, and able to access, support to help them manage the challenges of working while living with a progressive condition. In particular, they require support from clinicians to move through the on-going journey of work changes that will be necessary to enable them to continue working. A key focus for clinicians should be the issues around acceptance, disclosure and promoting clients to maintain control of their choices. Access to support services at present is lacking and inconsistent in New Zealand, this needs to be addressed if people with MS are going to be successfully supported to remain in work and continue to experience the benefits of work. Further research is required to explore what support services are required and in what form these support services should be provided.

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## Appendix 1 - Critique of background literature using the CASP tool

Table A1.1: Critique of Cross-sectional studies using the CASP tool

Article	Benedict et al, 2014	Bishop et al, 2013	Bishop et al, 2015	Cadden and Arnett, 2015	Chiu et al, 2015	Forbes et al, 2006	Glad et al, 2011	Glanz et al, 2012	Goverover et al, 2015	Honarmand et al, 2011	Julian et al, 2008
Y = Yes, N= No, CT = Can't tell											
Did the study address a clearly focused issue?	Y	Y	Y	Y	Y	Y	Y	Y	Y	CT	Y
Did the authors use an appropriate method to answer their question?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Were the subjects recruited in an acceptable way?	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Were the measures accurately measured to reduce bias?	Y	Y	Y	CT	Y	Y	Y	Y	CT	Y	CT
Were the data collected in a way that addressed the research issue?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	CT
Did the study have enough participants to minimize the play of chance?	CT	Y	Y	Y	Y	Y	Y	Y	Y	CT	Y
How the results presented and what are the main results?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the data analysis sufficiently rigorous?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Can the results be applied to the local population?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
How valuable is the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Article Rating	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good

Table A1.1: Critique of Cross-sectional studies using the CASP tool (continued)

Article	Krause et al, 2013	Krokavcova et al, 2010	Krokavcova et al, 2012	McCabe and De Judicibus, 2003	Messer-Uccelli et al, 2009	Miller and Dishon, 2006	Moore et al, 2013	Morse et al, 2013	O'Connor et al, 2005	Pack et al, 2014	Patti et al, 2007
Did the study address a clearly focused issue?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Did the authors use an appropriate method to answer their question?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Were the subjects recruited in an acceptable way?	Y	Y	Y	Y	Y	Y	Y	CT	Y	Y	N
Were the measures accurately measured to reduce bias?	Y	Y	Y	N	N	Y	Y	N	Y	N	Y
Were the data collected in a way that addressed the research issue?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Did the study have enough participants to minimize the play of chance?	CT	CT	CT	CT	Y	Y	CT	N	CT	Y	Y
How the results presented and what are the main results?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the data analysis sufficiently rigorous?	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y
Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Can the results be applied to the local population?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
How valuable is the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Article Rating	Good	Good	Good	Good	Good	Good	Good	Fair	Good	Good	Good

Table A1.1: Critique of Cross-sectional studies using the CASP tool (continued)

Article	Phillips and Stuijbergen, 2006	Roessler et al, 2005	Roessler et al, 2011	Salter et al, 2010	Simmons, Tribe and McDonald, 2010	Smith and Arnett, 2005	Strober et al, 2012
Did the study address a clearly focused issue?	Y	Y	Y	Y	Y	Y	Y
Did the authors use an appropriate method to answer their question?	Y	Y	Y	Y	Y	Y	Y
Were the subjects recruited in an acceptable way?	Y	Y	Y	Y	Y	CT	CT
Were the measures accurately measured to reduce bias?	Y	Y	Y	Y	CT	Y	Y
Were the data collected in a way that addressed the research issue?	Y	Y	Y	Y	Y	Y	Y
Did the study have enough participants to minimize the play of chance?	Y	Y	CT	Y	Y	N	CT
How the results presented and what are the main results?	Y	Y	Y	Y	Y	Y	Y
Was the data analysis sufficiently rigorous?	Y	Y	N	Y	Y	Y	Y
Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y
Can the results be applied to the local population?	Y	Y	Y	Y	Y	Y	Y
How valuable is the research?	Y	Y	Y	Y	Y	Y	Y
Article Rating	Good	Good	Good	Good	Good	Good	Good

Tables A1.2: Critique of Systematic Review study using the CASP tool

<b>Article</b>	<b>Shahrbanian et al, 2013</b>
<b>Did the review address a clearly focused question?</b>	Y
<b>Did the authors look for the right type of papers?</b>	Y
<b>Do you think all the important, relevant studies were included?</b>	Y
<b>Did the review's authors do enough to assess the quality of the included studies?</b>	Y
<b>If the results of the review have been combined, was it reasonable to do so?</b>	Y
<b>What are the overall results of the review?</b>	Y
<b>How precise are the results?</b>	Y
<b>Can the results be applied to the local population?</b>	Y
<b>Were all important outcomes considered?</b>	Y
<b>Are the benefits worth the harms and costs?</b>	Y
<b>Article Rating</b>	Good

Tables A1.3: Critique of Cohort studies using the CASP tool

Article	Glad et al, 2011	Glanz et al, 2012	Krause et al, 2013	Miller and Dishon, 2006	Morrow et al, 2010
Did the study address a clearly focused issue?	Y	Y	Y	Y	Y
Was the cohort recruited in an acceptable way?	Y	Y	Y	Y	Y
Was the exposure accurately measured to minimise bias?	Y	Y	Y	Y	Y
Was the outcome accurately measured to minimise bias?	Y	Y	Y	Y	Y
Have the authors identified all important confounding factors?	CT	CT	CT	CT	CT
Have they taken account of the confounding factors in the design and/or analysis?	CT	CT	CT	CT	CT
Was the follow up of subjects complete enough?	N	N	N	N	Y
Was the follow up of subjects long enough?	N	N	N	N	N
What are the results of this study?	Y	Y	Y	Y	Y
How precise are the results?	Y	Y	Y	Y	Y
Do you believe the results?	Y	Y	Y	Y	Y
Can the results be applied to the local population?	Y	Y	Y	Y	Y
Do the results of this study fit with other available evidence?	Y	Y	Y	Y	Y
What are the implications of this study for practice?	N/A	N/A	N/A	N/A	N/A
Article Rating	Fair	Fair	Fair	Fair	Fair

Table A1.4: Critique of the Qualitative studies using the CASP tool

Article	Crooks, Stone and Owen, 2009	Crooks, Stone and Owen, 2011	O'Day. 1998	Johnson et al, 2004	Sweetland et al, 2007	Yorkston et al, 2003
Was there a clear statement of the aims of the research?	Y	Y	CT	Y	Y	Y
Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y
Was the research design appropriate to address the aims of the research?	Y	Y	Y	Y	Y	Y
Was the recruitment strategy appropriate to the aims of the research?	Y	Y	Y	Y	Y	Y
Was the data collected in a way that addressed the research issue?	Y	Y	CT	Y	Y	Y
Has the relationship between researcher and participants been adequately considered?	CT	CT	CT	CT	CT	Y
Have ethical issues been taken into consideration?	CT	Y	CT	Y	Y	Y
Was the data analysis sufficiently rigorous?	Y	Y	CT	Y	Y	Y
Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y
How valuable is the research?	Y	Y	CT	Y	Y	Y
Article rating	Good	Good	Poor	Good	Good	Good

## Appendix 2 – Ethics Approval letter



H15/037

Academic Services  
Manager, Academic Committee, Mr Gray Wirtz

21 May 2015

Dr W Levack  
Department of Rehabilitation Teaching and Research Unit (Wtn)  
School of Medicine  
University of Otago, Wellington

Dear Dr Levack,

I am again writing to you concerning your proposal entitled "Exploring the work experiences of people with Multiple Sclerosis", Ethics Committee reference number H15/037.

Thank you for your letter of 14th May 2015 addressing the issues raised by the Committee.

The Committee thanks you for confirming that Rachel Bladon has secured funding from the Research Committee of the Multiple Sclerosis and Parkinson's Society and also for noting that Rachel will not be directly involved with the recruitment of participants.

On the basis of this response, I am pleased to confirm that the proposal now has full ethical approval to proceed.

The standard conditions of approval for all human research projects reviewed and approved by the Committee are the following:

Conduct the research project strictly in accordance with the research proposal submitted and granted ethics approval, including any amendments required to be made to the proposal by the Human Research Ethics Committee.

Inform the Human Research Ethics Committee immediately of anything which may warrant review of ethics approval of the research project, including: serious or unexpected adverse effects on participants; unforeseen events that might affect continued ethical acceptability of the project; and a written report about these matters must be submitted to the Academic Committees Office by no later than the next working day after recognition of an adverse occurrence/event. Please note that in cases of adverse events an incident report should also be made to the Health and Safety Office:

<http://www.otago.ac.nz/healthandsafety/index.html>

Advise the Committee in writing as soon as practicable if the research project is discontinued.

Make no change to the project as approved in its entirety by the Committee, including any wording in any document approved as part of the project, without prior written approval of the Committee for any change. If you are applying for an amendment to your approved research, please email your request to the Academic Committees Office:

[gary.witte@otago.ac.nz](mailto:gary.witte@otago.ac.nz)

[jo.farronediaz@otago.ac.nz](mailto:jo.farronediaz@otago.ac.nz)

Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval or an extension of approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.

Yours sincerely,



Mr Gary Witte  
**Manager, Academic Committees**  
Tel: 479 8256  
Email: [gary.witte@otago.ac.nz](mailto:gary.witte@otago.ac.nz)

c.c. Assoc. Prof. W Taylor Department of Rehabilitation Teaching and Research Unit (Wtn)

### **Appendix 3 – Flyer advertising study**

Do you have Multiple Sclerosis (MS)? And are you in paid employment?

We are looking for people with MS who are working or have stopped work in the last six months, to participate in a research project exploring the work experience of people with MS.

It is hoped that by exploring this topic we will gain a better understanding of the effect of MS on employment. We also hope to identify ways that may help people with MS to remain in employment.

Participants of this project will be asked to complete an interview with the contact researcher. This interview will take approximately an hour, and will be completed in a location and at a time convenient to you. The interview will cover topics in relation to your work and how this has been since your diagnosis with MS.

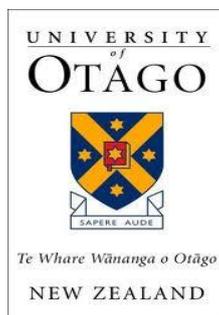
This project is being undertaken as part of the requirements for a Masters in Health Science, through the Rehabilitation Teaching and Research Unit, University of Otago.

Potential participants will need to be available for an interview between June and December 2015.

If you wish to find out further information and obtain a copy of the participant information sheet, please contact:

<b>Contact Researcher:</b>	<b>Name: Rachel Bladon</b> <b>Department: Multiple Sclerosis and Parkinson’s Society Canterbury</b> <b>Position: Physiotherapist</b>	<b>Contact phone number:</b> <b>03 3662857</b> <b>Contact email:</b> <b>r.bladon@ms-pd.org.nz</b>
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## **Appendix 4 – Participant information sheet**



<b>Study title:</b>	<b>What are the work experiences of people with Multiple Sclerosis? – A qualitative study.</b>	
<b>Contact Researcher:</b>	<b>Name: Rachel Bladon</b> <b>Department: Multiple Sclerosis and Parkinson’s Society Canterbury</b> <b>Position: Physiotherapist</b>	<b>Contact phone number:</b> <b>03 3662857</b>

### **INFORMATION SHEET FOR PARTICIPANTS**

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate.

If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

#### **The project aim:**

The aim of this project is to explore the work experiences of people with Multiple Sclerosis (MS). It is hoped that by exploring this topic we will gain a better understanding of the effect of MS on employment. We also hope to identify ways that may help people with MS to remain in employment.

This project is being undertaken as part of the requirements for a Masters in Health Science, through the Rehabilitation Teaching and Research Unit, University of Otago.

### **Who is funding this project?**

This study is being principally self-funded by the contact researcher as part of her Master's programme. Some additional funding has been sourced from the Multiple Sclerosis and Parkinson's Society Canterbury. Applications will be made to Physiotherapy New Zealand, the Neurology Special Interest Group of Physiotherapy New Zealand and the Canterbury Branch of Physiotherapy New Zealand later in 2015, to help secure further funding for the research.

### **What types of participants are needed for the project?**

This study requires people with a confirmed diagnosis of MS and who are in paid employment or have been employed in the last six months. People who are working full-time or part-time are invited to participate in this project. As this project focuses on the effects of MS on paid employment, people who have not worked for the last six months, or who have worked in voluntary or unpaid roles, will not be involved in the study.

It is hoped that between six to ten participants will be recruited for this project.

### **What will you be asked to do?**

Should you agree to take part in this project, you will be asked to complete an in-depth interview with the contact researcher. This interview will take approximately an hour, and will be completed in a location and at a time convenient to you. The interviewer is happy to travel to your home, workplace or any other location that you would prefer. Alternatively you can choose to come to the Multiple Sclerosis and Parkinson's Society's office for your interview. If you travel for your interview, you can be reimbursed for reasonable travel costs.

There will be no impact on your usual health care either by your refusal or agreement to participate in this study.

### **What data or information will be collected and what use will be made of it?**

To ensure accuracy of data, the interview will be recorded. The interview will be transcribed word by word by the researcher or a professional typist (who will have signed a confidentiality agreement). You will be allocated a project number to help maintain anonymity. Only the contact researcher will be aware of the project number allocation. Identifying information will not be available to anyone else but the contact researcher. The raw data/information gathered may also be seen by the university supervisor for this project. Names of people, places or organisations will be removed from the transcripts to make them anonymous.

Demographic information about all participants will be gathered, but this information will not be used to identify participants in the completed research. This demographic information will include age, gender, type of MS, type of work and hours worked.

The data from your interview will be reviewed to explore themes and ideas from your responses. These themes will be compared between all participants to help identify any common areas. It is hoped that these common themes will give us a better understanding of the effects of MS on employment. They will also be used to help identify ways that people with MS may be supported to remain in employment.

The anonymous interview transcripts from the research will be stored for at least ten years in a locked filing cabinet. Any personal information held on the participants such as contact details and audio tapes (after they have been transcribed) will be destroyed on the completion of the research.

The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve your anonymity.

Participants are welcome to view the data/information that relates to them at any stage in the research process. You are also welcome to see the results of the study. If you wish to view your data/information or the study results, you can request them from the contact researcher. The contact details for the contact researcher and supervisors are provided on this information sheet.

This project involves open ended questions to allow you to talk to us about what you think is most important. The questions however will include discussion of the following:

- How Multiple Sclerosis affects your employment/work
- How you manage work in relation to your MS
- Changes you have made at work due to your MS
- What might help people with MS stay in work should they wish to do so

The precise nature of all the questions which will be asked have not been determined in advance, but will depend on the way in which the interview develops. If you feel hesitant or uncomfortable about any of the questions at any point, you may decline to answer them.

### **Can you change your mind and withdraw from the project?**

You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind.

**What if you have any questions?**

If you have any questions about this project, either now or in the future, please feel free to contact:-

**Contact researcher:** *Rachel Bladon, Multiple Sclerosis and Parkinson's Society Canterbury*

Telephone Number: 03 366 2857      Email Address: [r.bladon@ms-pd.org.nz](mailto:r.bladon@ms-pd.org.nz)

**Study Supervisor:** *Dr William Levack, Rehabilitation Teaching and Research Unit, University of Otago*

Telephone Number: 04 918 6279 Email Address: [William.Levack@otago.ac.nz](mailto:William.Levack@otago.ac.nz)

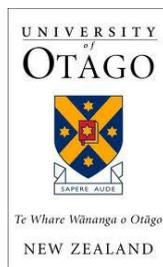
**Study Supervisor:** *Dr Hilda Mulligan, School of Physiotherapy, University of Otago*

Telephone Number: 03 364 3657 Email Address: [Hilda.Mulligan@otago.ac.nz](mailto:Hilda.Mulligan@otago.ac.nz)

This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph 03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

This study has received funding from the Multiple Sclerosis and Parkinson's Society Canterbury. We thank them for their support.

## Appendix 5 – Consent form



### **What are the work experiences of people with Multiple Sclerosis? – A qualitative study**

Contact Researcher: Rachel Bladon - [r.bladon@ms-pd.org.nz](mailto:r.bladon@ms-pd.org.nz)

03 3662857

#### CONSENT FORM FOR PARTICIPANTS

Name of participant:.....

1. I have read the Information Sheet concerning this study and understand the aims of this research project.
2. I have had sufficient time to think about my choice to participate in the study.
3. I have had an opportunity to ask questions about the study and what it involves.
4. I know who to contact if I have any further questions about the study.
5. I know that my participation in the project is entirely voluntary (my choice), and that I am free to withdraw from the project at any time without disadvantage.
6. I consent to the interview being audio-recorded.
7. I understand that the results of the project may be published and be available in the University of Otago Library, and that any personal identifying information will remain confidential between myself and the researchers during the study, and will not appear in any spoken or written report of the study.

I wish to receive a copy of the results. I understand that there may be a significant delay between data collection and the publication of the study results.	Yes / No
---	----------

Signature of participant:

Date:

## **Appendix 6 – Interview schedule**

This Interview schedule outlines possible questions, not all questions will be asked and alternate questions may be asked dependent on how the interview develops. Main questions written in black, prompts written in red.

General prompts - How do you feel about that? What do you think about that?

**1. Please will you tell me about how Multiple Sclerosis affects you?**

Prompts - Physically, mentally, emotionally, quality of life, life roles,

**2. Please will you tell me about your job/work/employment?**

Prompts - Hours worked, environment of work space, roles at work, elements of job, career aspirations

**3. Can you please share with me how you find working since your diagnosis with MS?**

**4. What things make work harder for you?**

Prompts – Environment, work hours, role, others at work, fatigue

**5. Please can you tell me about any changes you or others have made at work because of living with MS?**

Prompts - Change in work hours, roles, job, use of equipment, strategies you have put in place

**6. What could you do to further improve the challenges you encounter at work?**

Prompts - Change in environment, work hours, role, delegation of tasks

**7. Have you told anyone at work that you have MS?**

What was that like for you?

Prompts - Reasons for/against disclosure of diagnosis, explore both employer and colleagues.

**8. How is your relationship with work colleagues?**

Prompts - Environment changes, work role changes, hours worked, employer/colleagues

**9. Would you feel comfortable seeking support for issues at work that you think are related to having MS?**

**10. When would this be and who would you look to for support?**

**11. How do you see your future, in terms of work?**

**Possible other questions:**

- Can you please tell me about how working impacts on other parts of your life?
- What do your family think about you working?

## **Appendix 7 – Key to transcription conventions**

The transcripts for this study reflected as closely as possible the actual words and speech patterns of the interview participants. Interview extracts have been edited to illustrate points for the purposes of this paper, but all editing has occurred with the intent of retaining the original meaning of the speech. Ellipses (...) have been used to indicate where speech was omitted. Square brackets [ ] were used to insert editorial notes or words not present on the audiotape. Rounded brackets ( ) were used to indicate where nonverbal sounds such as laughter occurred on tape. Em dashes (–) were used in the place of hanging phrases resulting in an incomplete sentence, interruption by another speaker, or where the speaker made a meaningful pause.