Working Together: Understanding Job Retention in Multiple Sclerosis

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Abstract

Multiple Sclerosis (MS) is commonly diagnosed during key years of paid employment, yet within 10 years up to 80% of people with MS are no longer employed. Previous literature has focused on physical, psychological, and cognitive factors that may contribute as barriers to work. Current UK legislation requires employers to make ‘reasonable adjustments’ for people who disclose a disability. However, people with MS (PwMS) continue to leave work earlier than expected. The aim of this study is to understand more about what helps or hinders PwMS who would like to stay in paid work. Specifically, this research seeks to explore how PwMS, their employers and healthcare professionals can work together to improve job retention in MS. In total, 24 semi-structured interviews were conducted with PwMS who are working, PwMS who have recently left work, and relevant employers and healthcare professionals. Data were analyzed using Critical Grounded Theory. Key themes are identified for each subset and discussed. A core model is synthesized which includes the perspectives of the key stakeholders. Facilitators and barriers to job retention for PwMS are identified at the individual, organisational, and societal levels. The core model identifies five key themes: *In/validation, Adjustment demands, Sense of control, Social relations at work,* and *Constructing social value.* Analysis from the Professional data (i.e., employers and healthcare professionals) provides insight to structures that influence these key themes; *Knowledge structures, Inter-organisational structures, Socio-relational structures, and Intra-organisational structures*. How interventions can best be targeted to reduce barriers to paid work for PwMS is discussed.

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Abbreviations

CASP – Critical Appraisal Skills Programme

CGT – Critical Grounded Theory

DDA – Disabilities Discrimination Act

DMT – Disease-modifying treatment

HCP – Healthcare Professional

IPA – Interpretative Phenomenological Analysis

MS – Multiple Sclerosis

NHS – National Health Service

PPMS – Primary progressive MS

PwMS – People with MS

RESMS – Rapidly evolving severe MS

RRMS – Relapsing-remitting MS

SPMS – Secondary progressive MS

SRR – Systematic Research Review

Chapter 1: Introduction

Introduction Summary

Multiple Sclerosis (MS) affects approximately 2.3 million people worldwide, and in the UK alone has a prevalence of more than 120,000 people (Mackenzie, Morant, Bloomfield, MacDonald, & O'Riordan). It is commonly diagnosed between the ages of 20 and 40 years, and on average a diagnosis is received at the age of 32 years (Gitto, 2017). This is a life stage during which important milestones tend to occur, particularly in regard to making decisions about work and forming a career pathway. However, employment rates for people with MS (PwMS) are significantly lower than the general population (All-Party Parliamentary Group for MS, 2016) and even noticeably lower compared with other chronic or life-limiting conditions (Doogan & Playford, 2014). Previous studies attempting to understand the correlates of this reduced job retention in the MS population have found that this continues to occur even in PwMS with low physical or cognitive impact (Honan, Brown, & Batchelor, 2015; Wicks, Ward, Stroud, Tennant, & Ford, 2016). Psychological factors and fatigue have been shown to be key barriers to successful job retention (Ford, Wicks, Stroud, & Tennant, 2019; O'Connor, Cano, Torrenta, Thompson, & Playford, 2005). Specifically, McFadden et al. (2012) have developed an MS-specific measure to help screen for risk of job loss, the Work Instability Scale (WIS); Work instability refers to "*the extent of any mismatch between functional (in)capacity and work demands at a point in time*" (p.863)

In the UK, the Equality Act (2010) includes legislation designed to protect people with disabilities from discrimination in the workplace. This includes the requirement of employers to make reasonable adjustments such that an employee is not significantly disadvantaged at work due to their condition. Reasonable adjustments may include physical access routes, such as installing a ramp or a stair lift. These can also be changes or reduction of working hours, as well as purchasing specialist equipment. Nonetheless, this legislation is open to interpretation and decisions about adjustments can vary from employer to employer.

Understanding the challenges and facilitators to employment retention for PwMS could aid development of interventions for those that want to stay in work, foster a more positive experience for those continuing work, as well as helping PwMS to make empowered decisions about their employment.

Epidemiology and Aetiology of Multiple Sclerosis

Multiple Sclerosis is an autoimmune disease in which the central nervous system can suffer 'attacks' on itself causing damage to the myelin sheath which surrounds nerve cells. This process of demyelination can cause temporary or lasting damage to the nerve tissue and this leads to an array of physical and cognitive symptoms. Among the most common symptoms of MS are sensory disturbances, vision abnormalities, motor issues, and fatigue (Browne, 2014). However, the clinical course of MS is highly individualistic. In addition, PwMS have a high rate of psychological comorbidities such as depression and anxiety. MS can follow either a relapsing-remitting or a progressive pathway. Relapsing-remitting MS (RRMS) is characterised by "relapses," or intense setbacks which can occur sporadically and may last from days to months. People with RRMS may see a sudden or gradual onset of worsening symptoms during these relapses, which later subside. Although people with RRMS go back into remission periods, their health is usually somewhat deteriorated compared to before the relapse as a result of damage to the nerve fibres (axons). The most common form of MS is the relapsing-remitting type. However, this will usually develop into secondary progressive MS. This transition has been reported to occur at a median of 16 years after onset (Leray, Moreau, Fromont, & Edan, 2016). The progressive type of MS does not follow the same relapsing remitting course as RRMS and people with a progressive form of MS will see a continual deterioration in their health. Primary progressive MS follows this continuous deterioration of health from the onset of symptoms.

MS is often characterised by the appearance of lesions in the white matter of the brain which can be seen on brain MRI. However, MS is often a complex and slow disease to diagnose following initial symptoms. Early symptoms of MS may not be immediately obvious as signs of MS. For example, fatigue, weakness, or dizziness can often suggest early signs of MS but may point to a host of potential diagnoses (Polman et al., 2011). In addition, lesions found in the white matter from MRI examination are also present in other common neurological conditions or even in some healthy individuals with e.g., migraine resulting in misdiagnosis (Nielsen, Korteweg, Barkhof, Uitdehaag, & Polman, 2005). Hence, the diagnostic process can be a long, stressful, and extremely uncertain time and even at this early stage people will find they need time off work for hospital appointments or sick days. Fortunately, revisions to the McDonald Criteria (2010) for diagnosis of MS, have reduced the time required for effective diagnosis and treatment of MS (Polman et al., 2011).

MS affects an estimated 2.3 million people worldwide and is most commonly diagnosed during the key working years of adult life (Browne, 2014). Average age of diagnosis is 30 years, with onset typically occurring between 20 – 40 years of age (Browne, 2014; Kornblith, la Rocca, & Baum, 1986). Risk of onset of MS is reduced after the age of 45 years (Mackenzie et al., 2014). Paediatric incidences of MS are rare, making only up to 5% of cases, although MS has been diagnosed as young as 10 months (Shinnar & Glauser, 2016).

Potential Risk Factors

The causes of MS are not yet fully understood. It appears that MS may occur due to a combination of genetic susceptibility and a prodromal period of exposure to certain environmental risk factors (Ramagopalan et al., 2010). The most prominent theories relate to environmental factors such as vitamin D intake, place of birth (Elian, Nightingale, & Dean, 1990) and smoking (Sloka et al 2011), as well as genetic risk factors and exposure to viruses (Gilden, 2005).

Since Goldberg (1974) first considered that MS may be linked to vitamin D deficiency, the potential associations have been disputed (Munger et al., 2004). Sloka et al.'s (2014) findings that UV radiation availability are correlated with MS prevalence appear to support this theory, with lower incidence of MS occurring in regions closer to the equator. However, as Lucas et al. (2011) contribute, latitudinal correlates of MS are not necessarily in direct relation to Vitamin D uptake, as skin type and levels of skin damage from sun exposure are also associated with MS risk. Although MS occurs in all regions across the globe, the areas of highest incidence reported are North America and Europe (Browne, 2014). Areas of low sunshine see a higher trend in occurrence with notably higher MS populations occurring in the highlands of Scotland and Scandinavia (Melcon, Correale, & Melcon, 2014). Countries with warmer climates see a much lower prevalence of MS although, interestingly, Australia bucks this trend (Browne, 2014). Eastern and Western Asian countries, as well as North Africa have low incidence of MS (Melcon et al., 2014). However, research by Dean and Elian (1997) found that whilst there is a relatively low incidence of MS in countries such as Pakistan and India, children of families from these regions that immigrate to England display higher incidence rates than their older relatives. This suggests a geographical rather than genetic cause. Further, Langer-Gould, Brara, Beaber, and Zhang (2013) found that Black women are at increased risk of MS; although this may suggest a link to Vitamin D, the same study found a reduced risk in Hispanic and Asian participants.

Although family studies imply a genetic risk factor for MS (Ebers, Sadovnick, & Risch, 1995), no definitive genomes have been identified. Rather than significant linkage to particular genes, MS is more likely a result of subtle effects of many different genetic variants (Chataway et al., 1998). A key difficulty with studying genetic risk for MS is inadequate availability of samples for twin studies. This said, the risk for MS has been shown to be 10-25 times greater for first-degree relatives (Ramagopalan et al., 2010). As relevant screening techniques have advanced, some studies have identified potential genetic markers, Interleukin-2 receptor alpha chain (IL2RA) and Interleukin-7 receptor subunit alpha (IL7Rα), both of which contribute to T cell regulation. Nevertheless, the variance linked to these genes accounts for only a small proportion of the risk of MS, and it is still unclear as to whether such genetic factors are responsible for initiating MS or just increase susceptibility to it (International Multiple Sclerosis Genetics Consortium, 2007).

Currently there is no cure for MS. In 1996 only one therapeutic drug was available for MS: Avonex (Interferon beta). However, today there are 14 licensed disease-modifying treatments for MS (MS Trust, 2019). Although these drugs do not halt the progression of the disease, they can slow the rate at which relapses reoccur, thus lowering the impact of the disease over time and reducing the risk of developing secondary progressive MS.

Multiple Sclerosis in the Context of Paid Employment

Although the majority of PwMS are working at time of diagnosis, within 10-15 years up to 80% are no longer in paid work (Kornblith et al., 1986; Rao et al., 1991). More recently, a MS society survey (All-Party Parliamentary Group for MS, 2016) observed that only 55% PwMS are in work compared with 75% of the general UK population although other surveys have found this figure to be even lower, ranging from 4-37% dependent on disease severity (Wetherly & McIntosh, 2016). These rates are similar in the USA with only 50% of PwMS in paid employment (Roessler et al., 2015). In fact, PwMS may lose an average of 19.4 years of paid employment (All-Party Parliamentary Group for MS, 2016). PwMS also report higher rates of unemployment in comparison with other chronic disabilities (Doogan & Playford, 2014), indicating that there may be distinctive barriers to work for this group. Despite this, a recent survey has seen that 53% PwMS who are not in paid employment "ideally, would like to work" (Wetherly & McIntosh, 2016). The benefits of remaining employed are well documented and include improved quality of life (Pack, Szirony, Kushner, & Bellaw, 2014), increased self-confidence (Johnson et al 2004), as well as financial security.

Barriers to maintaining work for PwMS include increased levels of physical disability (Bishop et al., 2015; van Gorp et al., 2019), MS symptom severity (particularly in progressive MS) and symptom persistence (Gerhard, Dorstyn, Murphy, & Roberts, 2020; Roessler, Fitzgerald, Rumrill, & Koch, 2001), disease-related factors such as mobility issues, visual issues, and fatigue (O'Connor et al., 2005; Rumrill Jr, Koch, & Wohlford, 2013); psychological factors including anxiety, depressive symptoms, and self-efficacy (Rumrill Jr, 1996; Wicks et al., 2016), higher perceived stress (Beier et al., 2019), cognitive impairment including executive functioning (Baughman, Basso, Sinclair, Combs, & Roper, 2015; Cadden & Arnett, 2015; van Gorp et al., 2019) and negative coping styles such as behavioural disengagement (Achterberg, Wind, de Boer, & Frings-Dresen, 2009; Strober, Chiaravalloti, & DeLuca, 2018). Grytten et al. (2017) found that PwMS who utilised avoidant coping mechanisms such as denial were likely to leave work sooner. Workplace barriers include difficulties navigating the worksite and employer reactions to disclosure (Gulick, Yam, & Touw, 1989; Munir, Randall, Yarker, & Nielsen).

On the other hand, PwMS who stay in work report higher self-efficacy and use of humour as a coping mechanism (Strober et al., 2018), increased quality of life and mood (Dorstyn, Roberts, Murphy, & Haub, 2019) and lower symptom incidence (Krause, Kern, Horntrich, & Ziemssen, 2013). Social support and higher core self-evaluations may mediate the impact of MS symptoms on employment insecurity (Iwanaga et al., 2018). PwMS who hold a higher level of education are more likely to find paid work (Gerhard et al., 2020) and stay in work (Roessler, Rumrill, & Fitzgerald, 2004). Similarly, socio-economic status can impact job opportunities, such that PwMS living in a lower socioeconomic context see reduced opportunities for paid work or work progression (Ciufia et al., 2018). Despite earning comparable salaries to their employment counterparts, PwMS see an increasing reduction in employment earnings by comparison to these counterparts in the years following diagnosis (Landfeldt et al., 2018a). In Australia, PwMS using higher efficiency disease-modifying treatments (DMTs) such as natalizumab and fingolimod were more likely to stay in work and do better at work (Chen, Taylor, & van der Mei). Indeed, early treatment with DMTs may reduce the likelihood of requiring disability retirement (Landfeldt et al., 2018b).

Johnson et al. (2004) found that, for PwMS, the benefits of staying in work often outweigh the costs and maintaining employment is an important factor in identity and mental wellbeing. It is therefore crucial to understand how to support and facilitate job retention in MS through identifying the potential for interventions at all levels suggested by the ubiquitous bio-psycho-social model.

The manager-employee dynamic has a critical impact on workers’ experience (Liden, Sparrowe, & Wayne, 1997) and employee perceptions of this relationship can have meaningful consequences for the employee’s self-worth (Deci, Connell, & Ryan, 1989). Manager-employee relations also appear to mediate organisational commitment (Liden, Wayne, & Sparrowe, 2000). Employees who feel they are treated fairly and have high job satisfaction are more likely to engage in extra-role behaviours (i.e., activities beyond the duties of their job role) in the workplace (Organ & Ryan, 1995).

Disease-related Factors

A UK-based study which looked at the impact of MS on employment retention (O'Connor et al., 2005), found that disease-related factors such as physical symptoms and fatigue were often cited as barriers to work stability. Raggi et al. (2016) found work difficulties to be associated with reduced ambulatory function and disease severity. Lower age at onset and disease duration have also been linked to job retention, with those with RRMS more likely to remain in work (Lunde et al., 2014).

Cognitive deficits affect up to 70% of PwMS (Ozakbas, 2015). Whilst prior research (Rao et al., 1991) has looked into cognitive impact on employment status in MS, Baughman et al. (2015) delve further to investigate performance within the employment setting, as measured both by the employee with MS and their supervisors. Employers rated technical and occupational performance of PwMS lower when they had higher cognitive impact. However, the interesting finding was that cognitively impaired individuals were rated more favourably than their colleagues when assessed for level of actions that cause deliberate harm to the employing organisation (e.g., wasting resources, arriving late). The authors speculate that employers may “feeling sorry for” employees who have difficulty performing technical tasks. Honan et al. (2015) found that *perceived* cognitive impairment can impact work retention, irrespective of actual cognitive abilities although other studies have found that deficits in cognitive function are linked to reduced work participation (Benedict et al., 2005; Morrow et al., 2010). Thus, further research is warranted into the relationship between cognitive function and work outcomes, and potential confounders or mediators that may lead to reduced work participation.

Psychological Factors

Interestingly, research is beginning to suggest that addressing the *psychological* symptoms of MS could lead to improved ability to work even when challenges are predominately physical. For example, Pagnini, Bosma, Phillips, and Langer (2014) reviewed the research on psychological interventions in MS and found positive effect in both psychological and physical symptoms, notably fatigue (see also Dennison, Moss-Morris, & Chalder, 2009; Grossman et al., 2010). In a study which preceded this PhD, the current researcher was part of a team that found an association between psychological variables and work instability (Wicks et al., 2016). Specifically, work instability was associated with depression and anxiety as well as reduced wellbeing, pessimism, low self-efficacy, and poor quality of life. Although further trajectory analysis found some of these associations to lessen, self-efficacy remained stable as a risk factor for work instability (Ford et al., 2019). This further supports studies which have found work performance consistently linked to self-efficacy (Gist & Mitchell, 1992; Wilski & Tasiemski, 2016). Low mood has also been associated with reduced work participation (Raggi et al., 2016). Hence, addressing these factors could help to reduce risk of job loss. Previous studies looking at psychological interventions for PwMS have shown that Cognitive-Behavioural Therapy and Group Therapy can show improved mood and psychological variables including self-efficacy (Lincoln et al., 2011).

Societal Factors

Qualitative studies have established how stigmatisation and perceived lack of support contribute to negative work outcomes for PwMS (Vickers, 2012; Yorkston et al., 2003). Perceptions of workplace environment can impact the decision to disclose MS to an employer, and as such, individuals who feel that their work environment is 'psychologically safe' are more likely to disclose their MS (Kirk-Brown & Van Dijk, 2014). Psychologically safe environments are those in which the employee feels trusted and respected and, hence, feel able to take potential interpersonal risks or discuss personal issues. Consequently, PwMS who do disclose tend to continue in work longer despite physical decline (Frndak et al., 2015; Kirk-Brown, Van Dijk, Simmons, Bourne, & Cooper, 2014). Disclosure can lead to increased work accommodations which may help the individual to continue working. However, PwMS are not always sure what accommodations they require or how to request these (O'Day, 1998) and accommodations that involve schedule adjustments or expensive devices are less likely to be granted (Rumrill, Fraser, & Johnson, 2013). In particular, PwMS report that available accommodations related to mental health needs in MS are not clear (Frndak et al., 2015).

To add to this, PwMS may delay disclosure until absolutely necessary (e.g., worsening symptoms or increased absence for hospital appointments) due to fear of stigmatisation (Reed, Meade, Jarnecke, Rumrill, & Krause). While increased physical impact appears to lead to increased likelihood of disclosing, it is cognitive and neuropsychological impairments that are more closely linked to reduced work participation (Benedict et al., 2005; Ford et al., 2019; Morrow et al., 2010). Conversely, Raggi et al. (2016) found limited evidence that non-supportive workplaces foster decreased work stability, but strong evidence that difficulties with interpersonal and social interactions are associated with difficulties staying in work.

Workplace policies and managerial attitudes may also have a role to play in employment outcomes for people with chronic illness (Charmaz, 2010; Werth, 2015). Negative managerial perceptions can filter down into the workforce creating a less supportive environment for people with disability (Williams-Whitt, 2007). The perception of the ideal worker within workplaces which is created around ableist norms has undermined the value of workers with chronic illness who, although they may not fit these social expectations, have their own set of skills to contribute (Foster & Wass, 2012). Women with chronic illness, in particular, may not conform to societal expectation due to caring responsibilities traditionally assigned to them (Vickers, 2012). While this is increasingly acknowledged, the perception of women as carers remains ingrained, further adding to the challenges of job retention faced by women with disability.

Employer response to disclosure of MS, specifically, is mixed. Some employers are able to implement appropriate adjustments, while others end up putting limitations to work, e.g., taking away responsibilities or opportunities (Reed et al., 2017). Kirk-Brown and Van Dijk (2014) found that employer responses to disclosure either focused on managing (assumed) disability or managing (assumed) ability. Disability-focused responses covered a range which included direct evidence of discrimination. By focusing on ability, employees felt trusted and appreciated, leading to increased sense of self-efficacy. It was not so much that PwMS were denying the impact of MS symptoms but rather that such responses resulted in increased optimism about managing these in the work environment. This study highlighted that it is not only unsupportive organisations that can reduce perceptions of psychological safety; paternalist responses such as making disability-focused assumptions can also negatively affect feelings of psychological safety. Although such managerial responses are often recognised as well-intentioned, and do not increase likelihood of employment reduction, the impact this has for pursuit of growth in work is negative. While pursuing occupational opportunities may be a lower priority for some, it is no doubt preferable to have these potentials available to the same degree as those employees without MS.

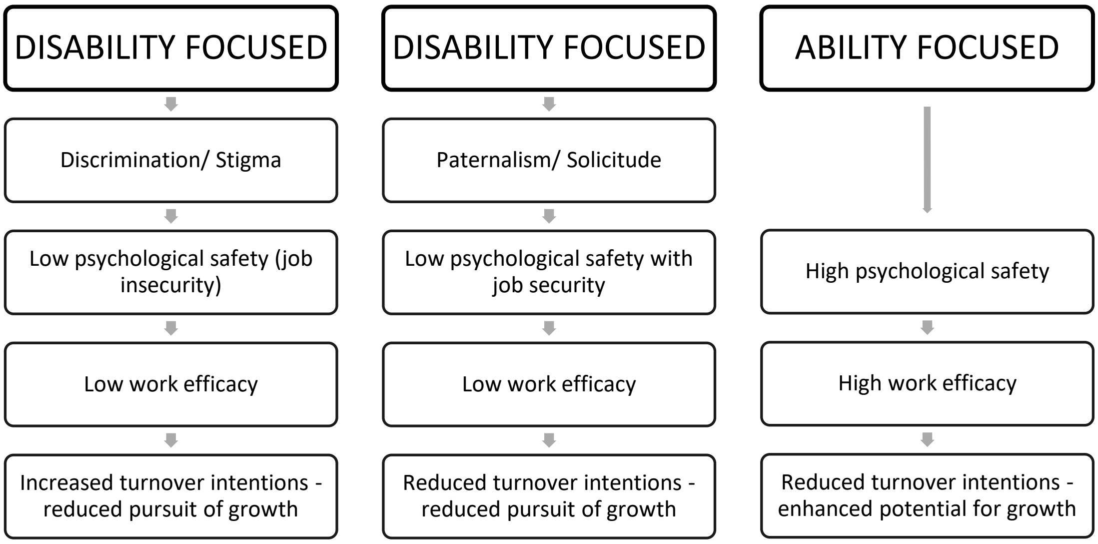

Figure 1.1 - Empowerment Model of Disclosure (Kirk-Brown & Van Dijk, 2014)

Workplace Accommodations

The benefits of workplace accommodations are threefold: employees with disability gain equal opportunities to maintain meaningful paid work which can have a positive influence on factors such as self-efficacy as well as the financial stability this affords. At the same time, employers are able to keep valuable and qualified employees, increase worker productivity and reduce potential costs of recruiting and training new employees. Furthermore, society as a whole benefits from an increased workforce, and the benefits this brings to the economy as well as societal wellbeing.

Barriers to workplace accommodation are usually due to lack of knowledge or lack of timeliness in delivering these effectively (Nevala, Pehkonen, Koskela, Ruusuvuori, & Anttila). Organizational policies and procedures also carry inherent ambiguities across the working world, making it difficult and stressful for those with disabilities to secure vital accommodations (Foster, 2007).

Current Disability Policies/Laws

It is important to provide information on relevant legislations to give context to the societal circumstances under which PwMS are participating in paid employment. Legislation related to disability discrimination and employment rights vary by country and this will have an impact on the experiences faced by PwMS. I focus here on the legislation in the developed, Anglophone countries: UK, USA, Canada, and Australia, but also consider The Netherlands to offer a perspective on a non-English-speaking European country. The Netherlands reports an incidence rate of nearly half that of the UK (88 compared with 164 per 100,000) yet equivalent reduced employment rates (77%) (Gitto, 2017). Both the UK and the Netherlands utilize social healthcare systems, although in the UK only 8% of PwMS are in full-time employment compared with 25% in the Netherlands; unlike the UK, the Netherlands does offer work incentives which may explain this contrast (Gitto, 2017). These five nations are also host to the literature included in the systematic review presented later in this thesis and therefore offer relevant context to the findings offered at that point.

The UK

The current enacted laws in the UK which aim to protect people with disability from discrimination are the Equality Act 2010 and the Disabilities Discrimination Act 1995 (DDA 1995). The Equality Act 2010 covers, for the most part, the same enactments as the DDA 1995, however the 2010 Equality Act covers all people who may be subject to discrimination based on gender, age, sexuality, disability, race or religion. With regard to employment rights, the UK legislation states that employers and service providers should be expected to make ‘reasonable adjustments’ to allow access to any property or service they provide so that people will not be disadvantaged as a result of their disability. Providing disclosure of the disability is made, an employer cannot discriminate against a person with disability, either by refusing them work or treating them less favourably due to their condition. The term ‘reasonable adjustment’ is a source of contention as it does not specify what could be deemed ‘reasonable’. However, it is generally understood that these adjustments would not be expected to be outside a realistic budget for the service provider and not clash with other regulations which are in place.

Issues arise in the context of employment when what constitutes reasonable adjustments can be entirely subjective. The literature also highlights that it can be unclear what reasonable accommodations are available to this effect (Bogenschutz, Rumrill Jr, Seward, Inge, & Hinterlong, 2016; Jellie, Sweetland, Riazi, Cano, & Playford, 2014; Meade, Reed, Rumrill, Aust, & Krause, 2016; Stone, Crooks, & Owen, 2013). For example, almost all participants in a study looking at a vocational rehabilitation intervention for PwMS reported that they had been unaware of the DWP Access to Work Taxi scheme, which provides help toward the cost of taxis for those who are unable to use public transport due to disability (Jellie et al., 2014). Bogenschutz et al. (2016), on the other hand, found that it was the employers that lacked knowledge of disability employment rights as well as how to utilize suitable accommodations to help employees with disability continue to work.

Administered by the Department for Work and Pensions, people with long-term disabilities are entitled to Personal Independence Payments (PIP) which have recently replaced the Disability Living Allowance. People with disability must apply for these and provide evidence that their disability prevents them from continuing their work. People who have not worked due to illness for more than 4 weeks can be referred by their employer to the governmental scheme ‘Fit for Work’ in which they undergo occupational health assessments to identify barriers preventing them from returning to work.

An unfortunate pitfall of PIP is that it does not take into consideration the fluctuating course that MS can take. According to the Money Advice Service information webpage on PIP: "*To get PIP, you must: Need help with everyday tasks or getting around, or both; Have needed this help for at least 3 months and expect to need it for at least another 9 months (unless you are terminally ill with less than six months to live)*" (Money Advice Service, 2018). MS is unpredictable and relapses can last between a few days to months, so this specification means that many PwMS are ineligible from these benefits until their MS has reached a progressive course.

USA

In the USA, the Americans with Disability Act 1990 (ADA 1990), revised by the Americans with Disability Amendments Act (ADAA 2008), inhibits discrimination against any person with disabilities, due to their disability, in areas such as employment, transport, public accommodations and access to government services. In addition, the US Equal Employment Opportunity Commission (EEOC) are responsible for enforcing Act 1 of the ADA 1990 which relates to employment and employers. Employers are prohibited from denying people with disabilities work or training by reason of their disability. Similarly, to the UK, the US Department of Labor requires that reasonable job accommodations should be made for employees with disabilities if they require it to conduct their work. Again, like the UK, the only stipulation of this is that these accommodations should not cause "undue hardship" on the employer. Employees with medical conditions that are expected to last more than one year, or to result in death, are entitled to Social Security payments. In order to receive these benefits, people must first complete a lengthy application which is expected to take 1 to 2 hours. It has been acknowledged that these assessments require significant reform in order to effectively measure for functional disability and encourage positive employment outcomes (SSA, 2017).

Canada

Canadians with disability are protected from discrimination under the Canadian Human Rights Act of 1977, which covers employment from the government and private companies. The Government of Canada policy on the Duty to Accommodate Persons with Disabilities in the Federal Public Service 2002 outlines that reasonable accommodations should be made for people with disability by way of identifying and removing barriers to work, unless doing so would cause undue hardship on the employer. This policy is in addition to the Employment Equity Act 1995 which specifies the obligations employers do and do not have to prevent discrimination against any group. Recently, the Canadian government began consultations on a Canadians with Disabilities Act which will aim to reduce under-employment for Canadians with disabilities as well as being proactive in preventing disability discrimination (McQuigge, 2017).

Australia

In Australia, the Australian Human Rights Commission (AHRC) was set up in 1986 to promote and protect human rights in Australia, including the Disability Discrimination Act 1992 (DDA 1992). The DDA 1992 in Australia states that anyone, regardless of disability, who can complete the "essential requirements" of a job should have equal opportunity to be considered for that job. Essential requirements include only the tasks that are specific to that role; for example, a telephone receptionist is required to be able to communicate over telephone, however they are not specifically required to hold the phone in their hand. This terminology appears to reduce some of the contention which was seen in the DDAs enacted by other regions regarding "reasonable adjustment".

The AHRC set out that:

> *"Employers should choose the best person for the job, whether that person has a disability or not. They should make this decision based on a person's ability to perform the essential activities of the job. They should not make assumptions about what a person can or cannot do because of a disability." – (Australian Human Rights Commission, 2017)*

Much like the previous Disability Discrimination Acts, the DDA 1992 includes the clause that workplace adjustments should not cause undue hardship for the employer. It is also made clear that it is the responsibility of the employer to thoroughly consider all possible adjustments, and if adjustments cannot be made, the employer is responsible for defending this decision.

Australia also completed a national inquiry called "Willing to Work" which was released in May 2016 and brought to light ongoing issues with discrimination against people with disability. A similar initiative was implemented by the UK government in 2016 when they released a 'Green Paper' for Work, Health and Disability. Although this public consultation led to the DWP revising employment support processes, some concerns arose regarding the negative impact some changes could have on the MS community (Wetherly & McIntosh, 2016). This inquiry was in parallel with the National Disability Strategy 2010-2020, a government initiative which aims to consult with the disabled community and set out a progressive plan for implementing relevant disability protection laws.

The Netherlands

In the Netherlands, the Equal Treatment of Disabled and Chronically Ill People Act (2003) gives people with disability rights to adaptations which would help them to remain participants in society. In terms of employment, the Disablement Benefits Act and the Self-Employed Disablement Benefits Act both give access to benefits for people in work who become disabled. The Netherlands also has a legislative act designed to help people with disability to re-enter the workforce. Disability is defined into individual categories in the Netherlands: Physical impairment, Psychogeriatric disorder (e.g., dementia), Mental impairment, Sensory impairment, Psychiatric disorder and Somatic (physical disorder). In 2015, the region underwent a transitional period as the Participation Act was introduced, alongside a Disability Job Appointment Quota which required employers to have a percentage of their workforce include disabled persons. The social agreement aims to have an additional 125,000 jobs for disabled people available by 2026. Employers that fail to meet the directives set out by these Acts will be levied under the Quota and Participant Law. However, it appears that this new legislation excludes those who have become disabled later in life (EBU, 2015).

Similar to the UK National Health Service (NHS), a publicly funded health insurance provides the majority of healthcare services, with entitlement to long-term medical care obtainable under the Exceptional Medical Expenses Act. In addition to national legislations, the United Nations Convention of Rights for Persons with Disabilities (CRPD 2006) is a human rights agreement that has gained 160 signatories and 89 ratifications to the optional protocol since it was opened for signature in 2007. The Convention sets out that countries will act to protect and encourage equality for persons with disabilities, including promoting independence and access to paid employment. This Convention has been signed in principle by the US, Ireland and the Netherlands. It has also been ratified by the UK and Australia, essentially meaning that these nations have agreed to be bound by the terms set out within it ("Convention on the Rights of Persons with Disabilities," 2017). Despite this treaty, and national legislation designed to combat discrimination and encourage positive working environments for people with disabilities, several studies are still finding that institutional discrimination is an ongoing concern, with managers failing to implement appropriate workplace adjustments or meet their legal obligations in this area (Foster, 2007).

Aim and Objectives of the Research presented in this Thesis

Psychological and other correlates of job retention in MS are only part of a complex picture which includes also the context within which PwMS are employed. Specifically, in the UK, by law, employers must make reasonable adjustments to mitigate the potential loss or limitation of opportunities for staff to take part on an equal level with others due to social and environmental barriers. Reasonable adjustments include changes to working hours which can be used to manage fatigue as well as environmental changes to accommodate physical challenges. Varekamp, Verbeek, and van Dijk (2006) reviewed interventions that can aid job retention for people with chronic health conditions, including empowerment methods. They conclude that there is some evidence that vocational rehabilitation can be effective in dealing with work-related problems, but more research is needed to understand the long-term effects of these interventions. More recently, Varekamp, Krol, and van Dijk (2011) assert that vocational rehabilitation interventions aiming at job retention for people with chronic health conditions is feasible and should include psychosocial factors such as empowerment. Varekamp et al., (2011) saw that an intervention aimed at increasing empowerment also led to increased self-efficacy in managing work- and diseases-related difficulties. This strengthens the case for further investigation into socio-contextual interventions aimed at job retention for PwMS.

In 2010, Diane Playford and Joanna Sweetland published a toolkit based on MS Society-funded research to help PwMS understand and manage potential barriers to stable employment, ‘Working Yet Worried’. This toolkit includes information and advice on legal issues, disclosure, managing symptoms such as fatigue and seeking emotional support, all of which were found to be common issues faced by PwMS who want to stay in employment. While this toolkit is extremely helpful in anticipating and addressing the potential difficulties of working with MS, the overview on dealing with psychological and emotional wellbeing does not provide a specific working model for an intervention strategy which deals with the psychological factors related to work instability. O’Connor et al. (2005) argue that it is important to develop a good working model that incorporates both healthcare systems and employment agencies for PwMS who want to stay in work.

Hence, the main aim of this research is to learn from PwMS, employers, and relevant health professionals about working together to facilitate job retention in MS. The secondary research questions underpinning this study are to understand what this combined wisdom might indicate with regard to the *forms* such interventions might take; to understand the broader limitations and facilitators in place to maintaining work for PwMS in the context of national and local policies; and to gain knowledge of the experiences of health professionals in this area.

This aim will be addressed through actioning the following objectives:

- To interview about 6-8 PwMS who are currently in employment despite challenges; aiming to describe what has helped and hindered each participant’s job retention and, from this, to create a picture regarding where best to target interventions and what these interventions should be.
- To interview about 6-8 PwMS who have recently stopped working due to their MS aiming to describe what has helped and hindered each participant’s job retention and, from this, to create a picture regarding where best to target interventions and what these interventions should be.
- To conduct about 6 interviews with relevant employers to understand what helps and hinders job retention in MS and, along with relevant policy documents, understand the wider context surrounding employment and MS to create a picture regarding where best to target interventions and what these interventions should be.
- To conduct about 6-8 interviews with relevant health professionals to understand what helps and hinders job retention in MS and, from this, to create a picture regarding where best to target interventions and what these interventions should be.
- To integrate the information obtained through these interviews and policy documents with a review of relevant literature to provide an evidence-based conceptualisation of interventions likely to facilitate job retention in MS.

This PhD research is original because it will make available, in condensed and practical form, the combined wisdom of PwMS, employers, and healthcare professionals who are working together to facilitate job retention in MS. With a greater appreciation of the PwMS-in-employment-context we hope to discover the points in the system amenable to intervention, how to capitalise on the successes already achieved by PwMS and employers in terms of interventions that work ‘on the ground’, and how to develop and utilize additional support from health professionals in an appropriate manner.

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Chapter 2: Systematic Research Review and Thematic Meta-synthesis

Introduction

There is a relatively well-established body of work looking at how the physical symptoms of MS can contribute to work insecurity, and more recently the effect of changes in cognitive functioning in relation to employment (Achterberg, Wind, de Boer, & Frings-Dresen, 2009; de Vries, Reneman, Groothoff, Geertzen, & Brouwer, 2012; Kornblith, La Rocca, & Baum, 1986; Raggi et al., 2016; Roessler, Rumrill Jr, Li, & Leslie, 2015; Uccelli, Specchia, Battaglia, & Miller, 2009). While recent work has established a significant impact of psychological symptoms of MS such as anxiety, self-efficacy as well as quality of life, pessimism and wellbeing (Baughman, Basso, Sinclair, Combs, & Roper, 2015; Ford, Wicks, Stroud, & Tennant, 2019; Kronstrom et al., 2011; Wicks, Ward, Stroud, Tennant, & Ford, 2016), such correlates of work instability make up only part of a more complex paradigm in which PwMS are trying to stay in work.

Understanding how success has been achieved by PwMS and their employers through existing narratives, I hope to identify how relevant interventions can be applied within the context of MS and employment. To inform and situate my research, I conducted a systematic review of the current literature. This will reveal where research has focused but also gaps that need to be addressed. The research question for this systematic research review (SRR) is: *What does evidence from qualitative studies tell us about the experience of employment for PwMS?*

Database Selection

A number of databases are available for collating related papers on this topic. Initially, the University of Leeds online library was accessed to note all ‘Psychology’ relevant databases. However, to complete an extensive strategy, additional databases were considered within the ‘Business and Economics’ subgroups. Databases were reviewed based on their description of content (Tables 2.1 and 2.2).

Table 2.1 - List of databases considered for literature searching

Database	Content
Cinahl	Comprehensive database for nursing and allied health journals, research material including health care books, select conference proceedings, evidence-based care sheet and quick lesson disease overviews.
Social Services Abstracts	Social Services Abstracts provides bibliographic coverage of current research focused on social work, human services, and related areas.
PsychInfo	Journal articles, books, dissertations and theses in core psychology disciplines, behavioural sciences and mental health

Medline	Journal articles and other reference types in medicine, dentistry and nursing, including biomedicine, medicine, nursing, dentistry, allied health, pre-clinical sciences. This includes material from across the biological and environmental sciences, psychology, and chemistry.
Web of Science	Journal articles in any of three databases; Science Citation Index, Social Science Citation Index and Arts and Humanities Citation Index.
Cochrane	Cochrane reviews are systematic reviews which represent the highest level of evidence on which to base clinical care.
ProQuest	The world's largest collection of dissertations and theses as well as global, national, regional and specialty newspapers, ebooks, journals and periodicals, digitized historical collections from libraries and museums, the Royal Archives, the Associated Press and the National Association for the Advancement of Colored People.
HMIC	A compilation of data from two sources; the Department of Health's Library and Information Services and King's Fund Information and Library Service.
Google scholar	Variety of sources, including academic publishers, universities, and preprint depositories.
EconLit	Economics and related subjects such as accounting, consumer economics, monetary policy, labour economics, marketing, economic theory and planning. It includes essays, research papers, books, dissertations, book reviews and working papers.
Nexis	Source of news information, including international newspapers, trade publications and company information

Table 2.2 - List of database search tools considered for literature searching

Database search tool	Content
OVID	PsycINFO 1806 to May Week 5 2017, Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present
EBSCOHost	CINHAL, ECONLIT, MEDLINE
ProQuest	ABI/INFORM Collection, Applied Social Sciences Index & Abstracts (ASSIA), British Periodicals, Film Index International, Linguistics and Language Behavior Abstracts (LLBA), PAIS Index, Periodicals Archive Online, ProQuest Dissertations & Theses: UK & Ireland, ProQuest Dissertations & Theses A&I, ProQuest Historical Newspapers: New York Amsterdam News, ProQuest Historical Newspapers: The Guardian and The Observer, ProQuest Historical, Newspapers: The New York Times, Sociological Abstracts, The Vogue Archive, Worldwide Political Science Abstracts
Web of Science	Web of Science Core Collection
Cochrane	Cochrane Database of Systematic Reviews

Creating and conducting searches

Before finalising the database list and key search terms, a librarian was consulted to discuss creating an effective search strategy. This included potentially useful databases and how to create a search strategy that remains broad enough to capture all potential literature whilst staying relevant to the research question. Key advice from this meeting was to remove Boolean search terms in relation to ‘qualitative methods’ as this may risk losing relevant articles due to the limited inclusion of these terms in the publishing of qualitative work, particularly for mixed method studies. Further, the librarian suggested to tailor the search strategy to each database in order to elicit more accurate findings. This involved beginning with the search terms (Table 2.3), and then exploding terms to explore more widely. As such, a search strategy was devised for each database and these are presented below. Any additional terms derived from this exploratory process were then entered for the previous saved searches and any that produced additional literature in the search were kept. Based on initial searches and an assessment of relevance, the final databases used for literature searching were Cinahl, PsychInfo, Medline, Web of Science, Cochrane, ProQuest and EconLit.

Table 2.3 - Key search terms

Cluster 1: Multiple Sclerosis			
1	Exp/ Multiple Sclerosis	3	Disabilit* OR disabled
2	Multiple sclerosis.tw		
Cluster 2: Employment			
4	Employ*	21	Access to work
5	Employment status	22	Accessibility
6	Unemploy*	23	Reasonable Adjustment
7	Self-employ*	24	Job
8	Reemployment	25	Jobseekers
9	Return* to work	26	Early retire*
10	Worksite OR workplace	27	Health related retirement
11	Supported employment	28	Equality Act
12	Absenteeism	29	Disability Discrimination
13	Employee assistance	30	Workplace Adjustment
14	Vocational AND rehabilitation	31	Disability leave OR sick leave
15	Human Resource Management	32	Occupation*
16	Work OR occupational adjustment	33	Disability Benefits
17	Work*	34	Welfare
18	Work Environment	35	Social welfare
19	Career	36	Corporate culture
20	Organi#ational culture		
Cluster 3: Qualitative			
37	Content Analys*	48	Qual* Method*
38	Phenomenolog*	49	Interpretative Phenomenological Analys*
39	Discourse OR Discourses	50	Subjective Experience*

40	Psychoanaly*	51	Interview
41	Focus Group?	52	Thematic Analys*
42	Qualit* Approach*	53	Lived Experience*
43	Framework Analys*	54	*psychological model
44	Qualit* Research*	55	*verbal communication
45	Grounded Theor*	56	narrative?
46	Qualit* Stud*	57	Story Complet*
47	Interpretat*		

Inclusion and Exclusion Criteria

There were three main inclusion criteria for this review: papers that reported results from qualitative method, including mixed design studies; a focus on participants with MS or those who managed them; and a focus on employment-related experiences. In order to keep a tight focus for this SRR articles exploring a wider population of ‘chronic illness’ or ‘disability’ were excluded. There were also a number of articles that reported on ‘occupations’ defined as ‘activities of daily living’ and included the daily challenges PwMS can experience, such as home and family duties. Unless it was considered that these articles contributed significant insights to employment experiences, these were also excluded. Unfortunately, due to this review making up part of a PhD programme of research, and thus being time and funding limited, translation services could not be considered and therefore all searches were limited to ‘English only’ papers. In order to ensure that a good quality standard is met, the searches were also limited to ‘peer-reviewed journal’. However, a small number of non-peer-reviewed texts of interest will be discussed to provide a wider picture of the research and potential findings in this area of literature. A search strategy was created and executed for the OVID (PyschInfo, Medline) and EBSCOHost (Cinahl, Medline) databases. Initially terms were mapped to headings to find relevant and applicable key terms within each database set. This method was used to tweak the search strategies to be relevant to each database. Final searches are in Appendix A. In addition, the reference lists of these articles were screened, as well as checking articles in which each paper was cited, to identify any relevant papers which may have been missed during the initial search stage.

Deduplication

Kwon et al. (2015) report that deduplication practices are most accurate within the built-in deduplication features of OVID and EBSCO databases. Hence, these methods were utilized to remove duplicate records initially. The resulting citations were then imported to Endnote where they were filed according to the database on which they were found. As Kwon et al. (2015) state, that Endnote has any notable discrepancies in duplicate record finding, the ‘duplicates’ identified during import were collected in a separate folder and checked by ‘hand’ to ensure accuracy. Although no false positives were identified in the duplicates folder, a ‘hand search’ of the remaining hits revealed that

120 false negatives were included in the primary folders. These were subsequently removed to give a final hit count of 2598 across all databases (Table 2.4).

Eyeballing

Once I had run the searches, I screened the titles for hits that were clearly not relevant to the research question. The two key elements I was looking to include were articles which focused on Multiple Sclerosis and Employment outcomes. At this stage, titles which made reference to employment, or chronic illness were kept unless Non-MS Illnesses were clearly mentioned. I did not want this review to detract from the specific nature of MS in employment. Papers which had titles related to genetic research, imaging studies, therapeutic trials and validity of measurements were discarded. This stage removed a significant number of hits. However, as it was unclear whether some papers were using qualitative or quantitative method, a second stage of screening abstracts was completed to remove those which did not include qualitative methods.

Table 2.4 - Article selection numbers at each stage for each database[1]

	OVID	EBSCO	ProQuest	Web of Science	Cochrane	Total
Initial hits	1990	1482	744	1222	182	5620
Limit to peer-reviewed and English language	1765	329	356	1081	44	3575
Remove duplicates on database system	1440	N/A	N/A	N/A	44	3250
Remove duplicated in endnote	1239	261	308	746	44	2598
Eyeballing	126	86	31	83	1	327
Abstract screen	14	6	5	6	0	31
Full text review - excluded	-2	-2	-1	0	0	-5
Full text review (total)	12	4	4	6	0	26
Scoping references and cited by	+1	0	+1	+2	0	+4
Total for full review	13	5	5	8	0	31

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[1] Table 2.4 includes details of the systematic search stages consistent with the itemised checklist for the PRISMA flow-chart, with the additional itemisation of articles by database. Reasons for exclusion are given under sub-heading *Inclusion and Exclusion Criteria*

Summary of Articles Included

A total of 31 articles were retained. The earliest work found was in 1989 with a consistent research output through to 2017 in which the SRR was conducted. A data extraction summary table was created (Table 2.5).

The first study, by Gulick, Yam, and Touw (1989) sampled a large group of PwMS (n=508) using both qualitative and quantitative methods. The study was looking to identify which factors made performing work difficult and those that made it easier. The qualitative phase used content analysis to build a brief description of the 53 conditions which were reported, with fatigue being the most prominent. Although Gulick et al.’s (1989) study considered task performance in a wider sense than paid employment, data sets were grouped by employed participants, homemakers, retired and unemployed. The employed group reported walking, vision and balance as barriers to work amongst other physical symptoms, as well ‘insufficient time’. Most commonly, this group cited intermittent rest and assistance from others as factors that enabled them to work.

A cluster of studies are then published in the 1990s. O'Day (1998) also used content analysis to understand the barriers faced by PwMS in maintaining paid employment. Severity of disability was a frequently cited barrier to working, with cognitive symptoms and societal attitudes also discussed. Salomone and O'Connell (1998) interviewed a sample of 12 (6 female: 6 male) to identify themes that influence career development for PwMS. Jongbloed (1998) focused on experiences of accessing income support for women with MS but is important for highlighting how these systems can contribute to employment experiences and decisions. Some women were afraid to return to work or felt unable to change their job due to the difficulties faced with securing adequate welfare support.

Research then continued into the 2000s. Dyck and Jongbloed (2000) focused on women with MS in employment and used a mixed method approach to describe the experiences women with MS have and the issues they face in maintaining employment. Yorkston et al. (2003) reports primarily on the practical elements of managing MS in the workplace. The study is limited to people with mild to moderate MS and, although this paper investigates completing tasks both at home and at work, there are findings which relate directly to employment experiences. Johnson et al. (2004) is another paper of the same study data as Yorkston et al. (2003), although this paper did not specify mild to moderate MS. Participants in this study gave examples of how working was interweaved with their identity and continuing employment gave them a sense of meaning. O'Connor, Cano, Ramio i Torrenta, Thompson, and Playford (2005) use qualitative interviews and content analysis to look at common factors that impact job retention for PwMS. Their findings from this mixed methods study were that symptoms, whether specific to one problem or broader in their impact, played a major role in the experiences of working with MS.

Continuing into the 21st century, Sweetland, Riazi, Cano, and Playford (2007) identified what PwMS wanted or needed from a vocational rehabilitation service. The two key needs highlighted concerned management of performance and expectations. Vickers (2009) presents a case study of a woman with MS who had negative work experiences following disclosure of her MS. Crooks, Dale Stone, and Owen (2009) report on the pilot phase of a study which uses semi-structured interviews to uncover strategies utilized by PwMS in academic roles to stay in work; their results for the full study are explored later in another paper included in this review (Crooks, Dale Stone, & Owen, 2011). A study by Cahill, Connolly, and Stapleton (2010) used the Occupational Performance History Interview-II (Kielhofner et al., 2004) to understand occupational adaptation for women with MS.

This review included three articles by Vickers published in 2012. In the first, Vickers (2012a) looks at disclosure of MS in the workplace through ‘ante-narratives’ (Boje, 2001) to explore the roles managers and colleagues play in job retention for PwMS and considerations of disclosure. Vickers (2012b) then aims to share a novel methodology to explore shame experiences of people working with MS. Using secondary phenomenological data analysis, she presents this work as creative non-fiction. The third Vickers (2012c) paper seeks to understand the impact of team processes for PwMS in the workplace using a single qualitative case study. McFadden et al. (2012) researched the concept of ‘work instability’ for PwMS, through a mixed methodology. The content analysis phase of this work concluded that PwMS felt that physical and cognitive barriers contribute to whether they remain in work. Rumrill Jr, Fraser, and Johnson (2013) presented results of telephone interviews investigating the experiences of PwMS who had made requests for workplace accommodations. Stone, Crooks, and Owen (2013) explored barriers and enablers to work for Canadian academics with MS. This mixed methods study used narratives to explore and summarise accommodation needs, how these participants managed their workplace environments as well as institutional barriers they faced.

In terms of the most recent research, in 2014, Vickers extended on her previous work conducting secondary phenomenological analysis, making comparisons between the experiences described by Hughes (1962) of the 'dirty worker' and employees with MS. Kirk-Brown and Van Dijk (2014) investigated the types of psychosocial support that PwMS might require following disclosure at work, through both semi-structured interviews and focus groups. Using iterative grounded theory, the authors noted that negative effects of disclosure included discrimination and disability-focused responses from supervisors while ability-focused responses were beneficial to continuing work. Jellie, Sweetland, Riazi, Cano, and Playford (2014) used semi-structured interviews with 8-week post-intervention interviews to explore the impact of a patient-designed vocational rehabilitation intervention. This paper also highlights key barriers PwMS faced in the context of working with MS. Coyne, Boscoe, Currie, Landrian, and Wandstrat (2015) reported key factors, which lead to PwMS reducing or ending their employment, using data from 27 semi-structured interviews and content analysis. Vickers (2015a) further explores the concept of the 'dirty worker' in the format of creative interpretive writing. In another piece of work Vickers (2015b) looks at a single case of one woman to explore the experience of workplace bullying due to MS. van Capelle, Visser, and Vosman (2015) investigated the experiences that were of most importance to people with early-stage MS in their working lives. This paper was unique in this review in using interpretive phenomenological analysis (IPA).

And finally, coming right up to date, Bogenschutz, Inge, Rumrill, Hinterlong, and Seward (2016) conduct telephone focus groups to investigate themes associated with what helps and hinders PwMS to stay in work. This paper was perhaps the closest to my research question, and being the most recent, provides useful insights in relation to this research. Meade, Reed, Rumrill, Aust, and Krause (2016) conducted focus groups (n=74) to gain insights into the perspectives of PwMS with physical disability regarding employment outcomes. A final paper in this review by Vickers (2017) looks at metaphorical masks that PwMS wear in the workplace which she argues are often used to draw attention away from this stigmatised illness. And most recently, van der Meide, Gorp, van der Hiele, and Visser (2017) looked at the meaning of work for people with relapsing-remitting MS, and the barriers and facilitators for them to stay in work through narrative interviews.

It is worth noting that, although this SRR selected 31 articles, there were some in which the authors reported different aspects of the same data set or study. Therefore, although 31 papers are reported, there were only 21 data sets. Jongbloed (1998) and Dyck and Jongbloed (2000) are publications created from the same dataset. The two papers by Crooks et al. (2009, 2011) were also outputs from the same study: one paper focusing on the pilot phase and the latter discussing the full dataset, with a further paper also published from this dataset (Stone et al., 2013). Vickers accounts for nearly one third of the papers in this review with six articles (2008, 2009, 2012a, 2012b, 2012c, & 2015b) all using data from the one larger data set, some focussing on specific case studies. Vickers 2014 and 2017 are also from one study while 2015a appears to be distinct, but this is not entirely clear from the methodology described. Although Rumrill appears in a number of research groups, with the earliest in this review being in 2013, the articles selected all seem to be from separate data sets. However, his colleague, Kurt Johnson sees two earlier works in this review along with Kathryn Yorkston, of which both are from the same dataset (Johnson et al., 2004; Yorkston et al., 2003).

The SRR also revealed there to be a number of research groups publishing in this area. Most notably, this review found 9 papers from Margaret Vickers, an Australian research academic with a diagnosis of MS and an intrinsic interest in how societal constructs impact the experiences of MS. In the USA, K. L. Johnson along with Yorkston, Klasner, Amtmann and Kuehn are producing some valuable output at the turn of the 21st century. This work then appears to be continued or merged with Phillip Rumrill, who, although only saw one paper appear in this SRR, has made a considerable contribution to the quantitative literature in MS and employment factors (e.g. Inge, Cimera, Rumrill Jr, & Revell, 2016; Roessler, Fitzgerald, Rumrill Jr, & Koch, 2001; Roessler, Neath, McMahon, & Rumrill Jr, 2007; Roessler et al., 2015; Rumrill Jr, 1996; Rumrill Jr, Koch, & Wohlford, 2013; Rumrill Jr, Roessler, Unger, & Vierstra, 2004). Joanna Sweetland and Diane

Playford are UK-based researchers who have made important contributions to the qualitative literature on MS and have used their findings to produce a layman's handbook, "Working Yet Worried" (2010) which provides useful and practical information to PwMS. In the Netherlands, Visser has collaborated with a number of other researchers to produce two of the papers that appear in this review, while Crooks and his colleagues are representing the Canadian perspective in this area.

CASP scoring

Once the articles to include were finalised, each article was assessed for quality. The Critical Appraisal Skill Programme (CASP, 2013) is an 8-item set designed to assess quality and rigour of qualitative research. I adapted the scoring to a 16-point system such that each item was given a mark of either 0 (no evidence), 1 (somewhat evident) or 2 (clearly evident) and the tally provided a final score of quality (Appendix A.2). This allowed me to distinguish the relative value of each article to a more detailed degree.

In order to increase rigour of the CASP scoring, after I had completed the initial evaluation, a selection of articles was assessed again independently by my academic supervisor (Appendix A.3). In the first round, my supervisor assessed five articles, which I selected purposively, to include a diverse range based on my initial CASP score, as well as to include a range of the years covered by the articles. We then discussed our assessments and agreed CASP scores for these articles. This process revealed some systematic inconsistencies in my scoring on some CASP items. For example, when considering the item '*Has the relationship between researcher and participants been adequately considered?'* it emerged that for some articles, I was confounding this score with rigour of the analysis. Following this, I reviewed the remainder of my CASP scores to increase consistency for these items. A second set of five articles were then sent to the second assessor for a further round of independent CASP scores. Again, I aimed to include a purposively diverse range of scores, but intentionally included certain articles that I felt had been less clear-cut. This process was repeated until both researchers were independently scoring all articles with a discrepancy of 1 or less, the final round consisting of two articles I had found difficult to assess. This resulted in a total 17 of the 31 papers undergoing double assessment so increasing the consistency of the CASP scoring and adding validity to the assessment. CASP scores for each article can be found in the data extraction table (Table 2.5).

CASP scores for the 31 articles averaged 13 (ranging from 8-15) out of a maximum score of 16. Prior to 2000, only 4 articles were found with a mean score of 12. Between 2000 and 2009, a total of 8 publications were included with the CASP score averaging at 13. From 2010 to the present, 19 articles were found, mean CASP score 13, showing that there has been a keen rise in interest within this area of research with a very slight upward trend in quality. It is worth noting however, that a significant proportion of these later articles are from Vickers, as mentioned above produced several papers reporting on the various aspects of just a few data sets.

Noticeably, an area that many authors ‘fell down’ on was recognition of the impact of the relationship between the participant and the researcher. That is, by understanding something about the researcher vis-à-vis the research, the reader can make some assessment about their starting position and how their assumptions may influence the findings. For example, Braun and Clarke (2006) state that “*if we do not know how people went about analysing their data, or what assumptions informed their analysis it is difficult to evaluate their research*” (p.80). Good qualitative research includes recognising one’s own assumptions, which can be influenced by background, status or knowledge. Only two articles documented an author with a disability; whilst Vickers directly discloses a diagnosis of MS, Crooks et al. (2011) note that one author has MS and another also a disability. Vickers argues strongly for the value of what she terms ‘insider research’, here research by PwMS about PwMS, suggesting that this creates richer data because participants talk more openly about their experiences. On the other hand, there is also an argument that ‘insider research’ is prone to the researcher interpreting participant experiences overly in-line with their own and failing to articulate key information due to assumed shared understandings. For example, Vickers states that “*I knew what respondents were talking about for the most part having experienced it, feared it, lived it or, at the very least, read about what they were telling me*” (Vickers, 2014b, p. 5). It is important to make sure that the participant expresses their experiences clearly and in detail in their own words and not give too much weight to presumed mutual understandings.

Table 2.5 - Data extraction table

#	Author(s), Year Country CASP Score	Aim	Data collection Data analysis Sampling Technique	Sample	Key themes
	Gulick et al. (1989) USA 13	To determine what conditions, impede or enhance the ability of persons with MS to perform work inside and outside the home.	Self-report questionnaire (2 open questions) Content analysis (Krippendorff, 1980) Random sampling	508 PwMS; employed, homemaker, unemployed, retired	Physical restrictions, person-environment interaction, MS symptoms, self-assessment (patient perspective)
	O'Day (1998) USA 9	To investigate how programmatic, personal and societal barriers, keep most people with MS from working.	Structured qualitative interviews Content analysis (Seidel et al 1995) Convenience sampling	16 PwMS with fatigue; unemployed but wanting to work	Personal barriers, societal barriers, programmatic barriers to work.
	Salomone and O'Connell (1998) USA 13	To gather information concerning the manner and extent to which MS influences the career development of people who contract the disease.	Qualitative semi-structured interviews Thematic analysis (Bogdan and Biklen, 1982) Stratified random sampling	12 PwMS employed and unemployed	The meaning of career and work; understanding of career, purpose of work, importance of job/work and work values, needs and personal qualities. The implications of MS; living with disability, the meaning of disability, barriers associated with disability.
	Jongbloed (1998) Canada 11	To identify the primary programmes of income support for women with MS who are no longer in paid employment, to examine their access and adequacy of benefits, the ways in which MS symptoms influence the need for, and access to income support, and to document the impact of these programmes on their lives.	Semi structured in depth interviews (Glaser & Strauss, 1967) Thematic (Glaser & Strauss 1967) Convenience sampling	23 PwMS employed and unemployed	Accessing benefits, adequacy of benefits, other constraints and fatigue
	Dyck and Jongbloed (2000) Canada 12	Learn from women’s experiences about factors affecting their employment after MS diagnosis, unravel the complex interconnections between these experiences and the different dimensions of the environment shaping them	In-depth interviews Constant comparative (Hammersley & Atkinson, 1995) Convenience sampling	31 Women with MS in paid employment or no longer working	Financial security, social identity (& disclosure), disease related factors, family and household duties, employment conditions (modifications and flexibility), workplace culture and attitudes
	Yorkston et al. (2003) USA 15	To examine the experiences of individuals with mild to moderate MS as they carry out everyday work activities both inside and outside the home.	Semi-structure interviews Thematic coding (Benner, 1994) Convenience sampling	14 People with mild to moderate MS.	The first theme, Defining the work, included Priorities: seeing what’s important; Plans: learning about resources and requirements; and Perspectives: fixing it yourself. The second theme, Changing how things get done, included Precipitating factors;

				Awareness; Constructing the strategies; and Evaluating the strategies.
Johnson et al. (2004) USA 15	To attain a better understanding of the benefits and barriers faced by persons with multiple sclerosis (MS) in the workplace.	semi structured interviews Thematic coding (Benner, 1994) Convenience sampling	16 PwMS	The cost-benefit economy of working; fatigue and cognitive changes; stress in the workplace; and accommodations made to address barriers. Stress as a feeling influenced by the environment, exceeding one's resources and interfering with performance at work.
O'Connor et al. (2005) UK 14	To identify factors that impact on work retention in patients with MS	Qualitative interview supplemented by open-question survey Content analysis Convenience sampling	62 PwMS employed	The person and their disease; and societal and employment environments.
(Sweetland et al., 2007) UK 13	To identify what PwMS require from a vocational rehabilitation service in terms of content and service delivery	Focus groups Thematic coding (Winmax) Convenience sampling	24 PwMS employed	Managing performance; improving performance, compensating for performance, modifying performance. Managing social and personal expectations; support with disclosure, support with issues around discrimination and lack of knowledge, service delivery, service promotion
(Crooks et al., 2009) Canada 12	To explore what it is about the specific workplaces in which MS workers are employed that facilitates employment outcomes.	semi-structured interviews (Holstein & Gubrium, 1995) Thematic analysis (Aronson, 1994) Convenience sampling	10 Academics with MS employed or retired	socio-spatial strategies related to travel; spatio-temporal routines, and social networks; flexibility, access to resources, and symptom fluctuation
(Vickers, 2009) Australia 13	To present a case study of a woman diagnosed with multiple sclerosis (MS) who was bullied out of her workplace	Qualitative interview (de Laine, 1989, 1997) Narrative reflexivity (Clegg & Hardy, 1996 Case study of one particular case of author's interest	1 Female with MS	Bullying at work, Disability discrimination, bullying/ undermining tactics
(Cahill et al., 2010) Ireland 14	To explore the occupational adaptation of women with MS.	Occupational Performance History Interview-II (Kielhofner et al 2004) Thematic analysis (Braun & Clarke 2006) Convenience sampling	7 Women with MS	impact of MS on the worker role and impact on personal roles
(Crooks et al., 2011) Canada 14	To detail the problem-focused coping strategies that academics with MS employ to enable them to teach in universities	Semi structure interviews Thematic analysis (Aronson, 1994) Snowball sampling	45 PwMS employed or retired	Coping strategies: Organizational, before/after teaching, during teaching.

(Vickers, 2012a) Australia 15	To depict aspects, perspectives and issues that surround the lived experience of whether or not one should disclose that one has MS at one's place of work	In-depth phenomenological interviews Anternarratives (Boje 2001) Not stated	20 PwMS; employed or no longer employed but have worked since their diagnosis	Self-disclosure of MS at work, professional identity, financial security, assumptions/discrimination about disabilities
(Vickers, 2012b) Australia 10	To share a novel qualitative methodological approach, interrogate shame experiences for workers with MS and offer evidence that shame experiences for workers with MS are potentially responsible for their unnecessary suffering, and premature withdrawal from work	Interview data as case studies (Sarantakos, 1993) Phenomenological secondary analysis (Zickmund, 2003): content analysis (Cavana et al, 2001) Secondary data from previous interviews	1 Male with MS	Shame Experiences: Contexts of shame, Narratives of shame, Scenes of shame
(McFadden et al., 2012) UK 14	To explore the concept of work instability following the inset of MS and develop an appropriate scale	Qualitative interviews Content analysis Purposive sampling	27 PwMS in employment	Physical and cognitive aspects of the disease and their impact upon work, Working environment and organizational aspects, Social aspects of the working environment, Psychological aspects of working
(Vickers, 2012c) Australia 9	To explore the impact of team processes on workers with MS by presenting a case of stigmatisation that can arise for people with MS working in a team	Single qualitative case study from in-depth interview (Ruddin 2006) Insider narrative. Not specified but reference to Sarantakos 1993 Not stated	1 Female with MS	Stigmatisation at work
(Rumrill Jr, Fraser, et al., 2013) USA 14	To explore experiences and outcomes for PwMS who sought assistance from Employment Assistance Services	Survey (telephone) Open selective and axial coding (Bellini & Rumrill, 2009) for qualitative data. Qualitative data presented as descriptives Purposive sampling	41 PwMS who had accessed employment services	Nature of job concerns; accommodations provided and reasons for job accommodation success.
(Stone et al., 2013) Canada 14	To investigate how academics with MS negotiate the socio-spatial workplace environment; how systemic institutional barriers and enablers in university workplaces shape their experiences and employment outcomes; and explore the	Semi structured telephone interview Thematic (Aronson, 1994) Snowball sampling	35 PwMS	Reasons for not pursuing accommodations, surreptitious inquiries regarding accommodations, responses to requests for accommodations, disclosure and getting needs accommodated.

	role(s) that gender plays in shaping their career paths.			
(Vickers, 2014a) Australia 10	To extend contemporary thinking around Hughes' (1958) and Goffman's (1963) ideas about 'dirty work' and stigma, with a view to enhancing understanding of disabled workers' experiences.	In-depth qualitative interviews Secondary thematic analysis of case studies (de Laine, 1997; Stake, 2000) Quota sampling (Jackson, 1995)	2 PwMS	Physical taint, social taint, moral taint
(Vickers, 2014b) Australia 11	To explore why people with MS might really be leaving their place of work	Qualitative interviews Thematic analysis (Benner, 1985) Convenience sampling	20 PwMS	Clayton's choice
(Kirk-Brown & Van Dijk, 2014) Australia 14	To identify the types of psychosocial support that people with MS require post-disclosure, in order to maintain their employment status. In particular, roles of psychological safety and work-efficacy.	Semi structured interviews Inductive thematic / comparative (Miles & Huberman 1994) Convenience sampling	40 PwMS employed and not employed	Themes to emerge in organisational responses to disclosure were a focus on ability (leading to enhanced perceptions of psychological safety and higher work-efficacy) and focus on disability (leading to diminished psychological safety and reduced perceptions of work-efficacy).
(Jellie et al., 2014) UK 13	To examine the impact of a patient designed occupational therapy led vocational rehabilitation (VR) intervention on the experiences of people with multiple sclerosis (MS) who were experiencing work instability	Semi structured interviews Constant comparative (Glaser & Straus, 1987) Purposive sampling	19 PwMS who had complete VR intervention	Understanding my symptoms and their management in the workplace; Removing my anxieties; Understanding and influencing my employer; Managing my loss of confidence and Having professional support.
(Coyne et al., 2015) USA 11	To increase understanding of the key symptoms and factors leading patients with MS to leave work or reduce employment	Semi structured interviews Content analysis (no reference cited) convenience sampling	27 PwMS employed	Physical symptoms, cognitive symptoms, fatigue
(Vickers, 2015a) Australia 8	To present stories of people with MS who appear to have felt like dirty workers not due to their job, but their MS	Qualitative interviews Creative interpretive writing (McCurdy, 1973; Rowland et al, 1990) Not stated	3 PwMS	Disability and 'dirty' workers
(Vickers, 2015b) Australia 10	To explore the experiences of a woman with MS in order to enhance understanding of workplace bullying and disability	Phenomenological in-depth interviews A semi-fictional case study (Ricoeur, 1983) using "empathic identity" (Tierney, 1998: 56) Not stated	1 Female with MS	Disability and workplace bullying, multiple truths

(van Capelle et al., 2015) The Netherlands 15	To investigate how people with early stage MS experience their disease within their working lives (and voice the experiences that matter most for people with MS)	Conversational interviews IPA (Smith, 2009) Purposive sampling	10 People with early stage RRMS	The tiresome process of adjustment, inventing ways to do your work, feeling hurt about how others see your illness, avoiding applying for jobs, embracing retirement and mourning over lost work
(Bogenschutz et al., 2016) USA 15	To examine most commonly reported barriers to and facilitators of employment from the point of view of PwMS	Qualitative phone-administered focus groups Conventional content analysis (Hseih & Shannon, 2005) Quota sampling	27 PwMS	Future uncertainty; prospect of future decline, cognitive challenges. Sense of loss; competency questioned, self-confidence, career changes. Navigating the workplace; accommodations, learning to cope, benefits eligibility.
(Meade et al., 2016) USA 15	To gain the perspective of those with physical disability secondary to MS regarding the employment outcomes they percieved to be of greatest importance.	Focus groups, audio and video-recorded Coded in Nvivo by 2 authors Purposive sampling	74 PwMS	3 broad categories; Compensation, Personal well-being, Benefitting others. Themes: salary, support responsibilities and lifestyle, pay for health needs (inc medications), maintain health and wellness, something to do and a reason to get up, socializing and interacting with other people, pride and sense of accomplishment, identity, sense of purpose and direction, enjoyment, stress and burden, value added and general helping others, providing direct help or assistance, inspiring others.
(Vickers, 2017) Australia 14	To share initial understanding of a newly identified social construct re. what life is really like for PwMS	Semi structured interviews The Data Analysis Spiral (Creswell, 1998): interpretive thematic Convenience sampling	19 PwMS	Workplace masks: 1. I'm fine!, 2. I'm Happy!, 3. I'm better than the Others!
(van der Meide et al., 2017) The Netherlands 12	The aim of this study was to gain insight into the meaning of work in the everyday lives of people with relapsing-remitting MS, and the barriers and facilitators to staying in work	Narrative interviews Thematic (ATLAS.ti software; McCormack, 2000) Convenience sampling	19 PwMS	Becoming familiar with the disease (The strange body; Dealing with uncertainty; exploring boundaries), adjusting expectations (acting in accordance with boundaries; openness in the workplace; joint process and relying on each other; precarious balance), having an understanding and realistic line manager (leaving room for uncertainty; trusting relationship; taking care of the wellbeing of the employee; clear agreements), seeing work as meaningful life activity (changing meaning of work; being part of society and being meaningful; job satisfaction) and strategic considerations (occupational health service; financial motives; limited flexibility)

Thematic Meta-synthesis

Qualitative meta-synthesis is a growing field which has elicited a number of methodologies undergoing continual development and adaptation (Barnett-Page & Thomas, 2009; Thomas & Harden, 2008). These methods can vary depending on the conceptual framework from which one is approaching one's review and whether the researcher seeks to develop new theories or simply summarise the work that exists. As the extant research does not directly address my PhD research question: "*How can people with MS and their employers work together to improve job retention in MS?*" I am particularly interested in looking beyond the current data to uncover additional interpretation in relation to this question. To do this, I must step away from the theories developed by the authors and look at this collection of data from a naïve perspective. To do so, I conducted a Thematic Analysis of the findings (Braun & Clarke, 2006).

Relevant findings from the data extraction table created for the articles selected in the SRR (Table2.5) were sorted into groups of similarity. From this, patterns were identified in the findings of the extant research which were consolidated into themes and sub-themes and given descriptive labels. Initial analysis found five main themes with sub-themes as follows: (1) *Identity: Personal, Interpersonal, Societal;* (2) *Disease related factors: Physical, Cognitive, Fatigue;* (3) *Adjusting to life with MS: Effect on self, Prioritizing, Modifying work;* (4) *Workplace environment: Accommodations, Challenges;* and (5) *Financial security: Financial responsibilities, Accessing benefits.* However, this initial set of themes appeared to have gaps. For example, level of support and awareness of the legislation seemed important but were not adequately represented. Moreover, the theme *Identity* appeared to fit better as a sub-theme to *Social constructs*, alongside *Stigma of MS* and expectations of *Work norms*. And interpersonal and societal identity often merged into stigmatisation. Hence, it became more obvious through this first attempt that several important challenges of related to paid employment with MS at work were linked to workplace norms, stigmatisation, and social expectations.

A second attempt at thematisation was therefore undertaken. This took into account how, although MS symptoms span physical to cognitive, what was important in terms of job retention was managing these symptoms. Additionally, challenges and accommodations were appropriately labelled as spatio-temporal strategies given that barriers included travelling to and from work and daily work patterns. Hence, managing MS in paid employment seemed to fall into the two sub-themes of symptom management and spatio-temporal management: that is, adjusting to the changes imposed by the disease but also adapting one's environment to make it more manageable. Along with managing psychological impact, such as coping strategies and managing stress, these all fell into a broader category of managing the impact of MS. This second attempt resulted in four final meta-synthesis themes*:* (1) *Social attitudes/constructs: Stigma of MS, Identity,* and *Work norms*; (2) *Level of support: Help from others* and *Advocacy*; (3) *Managing impact of MS: Mental wellbeing, Symptoms,* and

Spatio-temporal strategies; and (4) *Labour rights*: *Awareness of legislation, Financial responsibilities,* and *Accessing benefits* (Table 2.6).

Other themes that could have been considered were invisibility of MS, health promotion, environmental barriers, and disclosure. Although these appeared in the research, it was concluded that they could be considered products of the broader themes. For example, invisibility of MS was discussed as a result of the stigma of MS and work norms. Participants felt the need to hide their symptoms for fear of negative consequences due to the social expectations of the workplace and the stigmatisation of disability. There were also some articles which mentioned fear and uncertainty, which are important factors to consider. The impact of these appeared to fall into the sub-theme of mental wellbeing as it was a factor of the coping strategies that seemed to impact on whether staying in work was a successful or detrimental experience.

Table 2.6 - Themes of the meta-synthesis by article of the systematic research review

<table>
<tr><th></th><th></th><th></th><th colspan="3">Social Attitudes/Constructs</th><th colspan="2">Level of Support</th><th colspan="3">Managing Impact of MS</th><th colspan="3">Labour Rights</th></tr>
<tr><th>#</th><th>Year</th><th>CASP</th><th>1a</th><th>1b</th><th>1c</th><th>2a</th><th>2b</th><th>3a</th><th>3b</th><th>3c</th><th>4a</th><th>4b</th><th>4c</th></tr>
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1a – Stigma of MS; 1b – Identity; 1c – Work norms; 2a – Help from others; 2b – Advocacy; 3a – (Mental) Wellbeing; 3b – Symptoms; 3c – Spatio-temporal strategies; 4a – Awareness of legislation; 4b – Financial responsibilities; 4c – Accessing benefits

Summary of the Themes and Sub-themes of the Meta-synthesis

The main findings of the extant literature selected in the SRR and thematised in the meta-synthesis are described in order following Table 2.6. Major themes and sub-themes are shown in Figure 2.1 below.

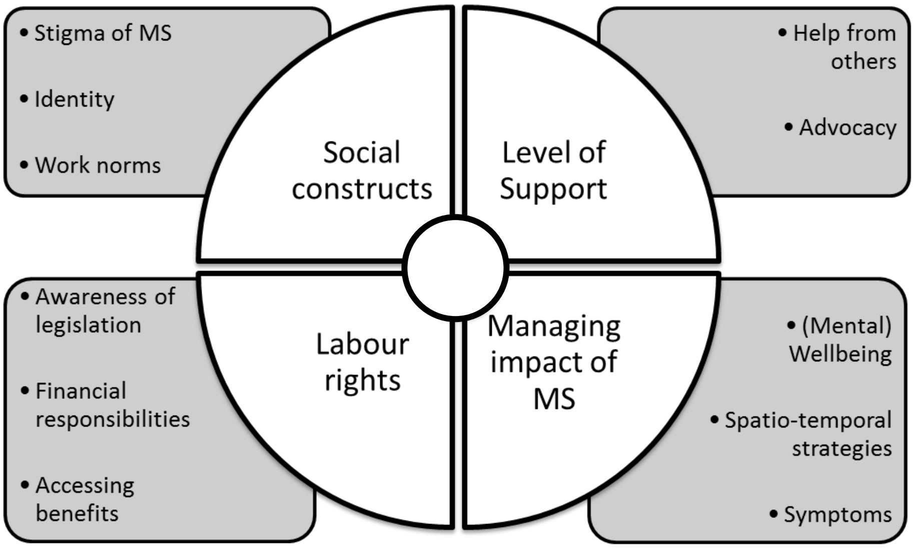

Figure 2.1 – Major themes and sub-themes of the meta-synthesis

Theme 1: Social Attitudes/Constructs (28 articles; Mean CASP 12)

Social barriers linked-in with decisions about disclosure. For some, this was related to the risks of being stigmatised or discriminated against, while some participants simply did not want to keep having to explain MS to people who did not understand:

> *"When I was fatigued in December, I just said I had a cold. It is just so much easier than trying to explain. People know about colds. Colds are real. But if I say I'm tired, people think that, well, everyone is tired." – Johnson et al. (2004) page 206*

This quote particularly shows how society still does not always appreciate or understand the impact of MS: "*Colds are real*" is stated as though MS is somehow an illegitimate reason for being under-par.

Theme 1: Social Attitudes/Constructs; Sub-theme 1: Stigma of MS (21 articles; Mean CASP 12)

Across many of the studies, participants discussed the lack of awareness surrounding MS and how this could negatively impact how those at work perceive them:

> *"…when you kind of walk unbalanced and people think you're drunk and you start to stagger or you start to slur your words because the nerve endings in your mouth can't pronounce the right words. People look at you and don't understand why you are acting that way" – O'Day (1998) page 141*

Participants reported how their competency at work came to be questioned following disclosure of their MS, due to misinformation or lack of understanding by employers about MS:

> *"Let me go because I'm not performing. I don't care about that. But, don't let me go because you think I'm too sick. That was a decision made by two people. They never discussed it with me."* – Bogenschutz et al. (2016) page 65

Not all stigmatisation results from intent to cause harm or to be malicious and some participants report how employers have made decisions on their behalf, due to concern, based on false assumptions about the person's MS:

> *"My supervisor told me, 'I am afraid that sometimes I hold back putting your name out there for promotion, because I worry about the toll stress would take on you.' She totally respects my work, but she was concerned because of my MS that the stress would be too much for me. So she didn't consider me for the promotion, or even inform me, and I would have been the best one for two of those jobs, and I should have been promoted."* – Johnson et al. (2004) page 206

Stigmatisation came in many forms, from false assumptions to more severe seeming neglect. For example, one participant was unable to return to work because an employer failed to make a minor adjustment to the building – which links also to the theme *Spatio-temporal strategies*:

> *"I did try to resume work, but I was told I couldn't, as the wheelchair couldn't be lifted up four steps to get in."* – O'Connor et al. (2005) page 894

Another form of stigma was bullying, and a concept that Vickers (2014) writes about called 'Clayton's choice'. Here Vickers is drawing from an Australian advert which appeared in the 1980s from the drinks brand 'Claytons' and included the tagline: "The drink you have when you're not having a drink". To this effect, she discusses the 'decision' to leave work when this is not actually the person's decision at all:

> *"Well, she said to me, 'I found this wonderful staff-room but I don't know how you're going to manage, Irene?' And I said, 'Well, all I can do is give it a go,' which I did. And at the end of one year I said, 'Look this isn't working for me.' And she said, 'Well, we can't take it back,' [whispering] and I believed her…and unfortunately the organizer for the Teacher's Federation, the Union, she said, 'Irene, be very careful. If you make too much fuss, they may retire you.' So I was really frightened. But after a year I just decided it was too much, and I just went and said to her, 'Look, I cannot cope with this.'"* – Vickers (2008) page 9.

This fear that PwMS face around their job security is a common phenomenon due to the stigmatisation chronic illness can bring and participants across the studies reported how they tried to mask their problems:

> *"Again, because I don't want that stigma around me, that I need special treatment…I sort of, 'soldier on.' If I'm feeling fatigued, I'm not a person that will sit there and go, 'Oh I need to lie down and take a rest for a while.'…I've never [asked for help or a rest], which is probably stupid. I don't know, but it's just something that I've always done."* – Vickers (2017) page 9

Theme 1: Social Attitudes/Constructs; Sub-theme 2: Identity (12 articles; Mean CASP 13)

Participants wanted to mask their MS, not only because of concerns about stigmatisation, but also because the changes they felt MS was having on their identity. Not only were participants concerned about how others perceived them, but they wanted to maintain their self-image and current role:

> *"I mean, it doesn't feel right…[but] I don't trust how they [her colleagues] are going to behave if I say I have MS. I don't trust that I will have my job again next year…Like it feels better to me when people know. And yet I have a really hard time telling…I have a feeling that it's much more about me than it is about them…I mean most of my life I was the one who had a lot of energy, and I can still fake it…someone was saying 'it's such a pleasure working with her, she has such, so much energy [emphasis added].'"* – Dyck & Jongbloed (2000) page 342

Participants talked about how continued employment gave them a sense of meaning:

> *"For many, work was important to their identity, self-esteem, and social contact. For example, GH reported that, 'I want to do a good job, and be valuable, and worthwhile. No matter how hard you try, a lot of your self-esteem is based on your work.'" – Johnson et al. (2004) page 203*

Hence, changing or adaptations to their work roles could result in losing the sense of meaning their job gave them:

> *"Being facilitated to continue in their work role with changes, such as reduced hours of work or altered work tasks, resulted in the participants experiencing dissatisfaction and a lack of personal meaning and value with their adapted work role:*
>
> *'Before I worked more and I worked differently. Then it was a career, now it's just a job. I don't enjoy it. I don't find it very challenging' (Geraldine)" – Cahill et al. (2010) page 111*

Concerns about identity manifested not just with regards to a diagnosis of MS, but also the identity that working provides. This links with the theme *Mental wellbeing*. In an attempt to maintain parts of their identity that are important to them, participants discussed how they continued to work despite this exacerbating their MS. This was noted particularly in women with MS who work outside the home, yet often continue also to shoulder the role of homemaker and caregiver:

> *"I could not handle that work load and being a mother. I really did try, I honestly did try but my fatigue level wouldn't allow me…I remember pushing myself a lot and I think that's why I had more exacerbation because I was trying to do it all. I was trying to work hard and make [my family] very proud of me, which I did." – O'Day (1998) page 141*

Identity issues are connected to the fact that MS can often be an 'invisible' illness and participants often mentioned how they try to conceal their disease in order to avoid a 'disabled' identity, showing that, even with legislations which aim to protect them, many PwMS still fear the possibility of stigmatisation at work if they are unable to conform to 'workplace norms'.

Theme 1: Social Attitudes/Constructs; Sub-theme 3: Work Norms (11 articles; Mean CASP 13)

The literature indicated that PwMS felt undervalued at work and to be considered 'less productive' workers as employers tended to focus on the negative aspects of job retention, such as the cost of assistive devices. However, this fear could be mitigated if PwMS could display the skills and experience which made them an invaluable employee:

> *"Modifications occurred most often when the woman had specialized skills, making her hard to replace, and/or had proven herself to be a valuable employee over time." – Dyck & Jongbloed (2000) page 34*

However, such strategies are based on 'ablest' constructs of what constitutes the 'ideal worker' and PwMS often find that they are able to continue working effectively regardless of sticking to an expected regime of how they conduct this work:

> *"MS doesn't really affect what I do, rather, how I do it." – Yorkston et al. (2003) page 374*

This is an important statement in summarizing how having MS is less about whether a person is 'able' but about requiring a different way of completing the work. Moreover, just because a way of working is usual, does not mean that it is the only effective method.

Theme 2: Level of Support (21 articles; Mean CASP 13)

The level of support, either through peer networks, having employers that advocated for them to stay in work, or direct help from others was very important for PwMS in continuing to work. PwMS found that having support had a positive influence:

> *"I think when I was working, of course we had a peer-support structure. You might not have seen everybody every day for a long period of time, but they were there and the camaraderie and those types of things always boosted you." - Meade et al. (2016) page 34*

Theme 2: Level of Support; Sub-theme 1: Help from Others (6 articles; Mean CASP 13)

PwMS find that having help from others can make a difference to staying in work:

> *"You notice the small things. Somebody at the office came to me and said: 'I asked you to draft that article, but, you know, I will just do it myself.' [Or] when I was assigned to a meeting, [I liked the fact that someone said to me], 'you know, I'll take that.'" – van Capelle et al. (2015), page 4*

Having friends and family who PwMS can rely on for support is an important resource:

> *"And if I had meetings at the far end of campus, I might get my husband to drop me off there instead of trying to get there myself. So it's made some changes in that regard." – Crooks et al. (2009), page 27*

Having help with tasks outside of paid employment, such as household chores, can be important for PwMS to manage their energy and time:

> *"Around the house my husband helps out a lot. We divvied up what I can and can't do. He'll do the vacuuming and the sweeping, he hands me items to dust and then he does the main dusting. We kind of work together on that" – Johnson et al. (2004) page 207*

This support from others allowed PwMS to reduce their levels of stress, and maintain a level of wellbeing that made continuing to work manageable:

> *"He's [husband] picked up a lot of the instrumental ADL [activities of daily living] functioning. He takes care of all of the bills now. I used to do that. A lot of that is related to work load too. But he has an incredible workload as well. I think he's done that to give me more relaxation time to reduce general stress." – Johnson et al. (2004) page 207*

Tasks that may appear mundane to able-bodied co-workers can become significant barriers in the daily work lives of PwMS without the help of others:

> *"She felt embarrassed, and unwanted (at least by some), when all she was doing was getting a cup of tea. No one offered to help her." – Vickers (2015a), page 87*

Theme 2: Level of Support; Sub-theme 2: Advocacy (20 articles; Mean CASP 13)

According to PwMS in many of the studies, key to remaining in paid employment was job flexibility and support from their employer. However, some employers, although perhaps well-meaning, can be experienced as overbearing in their attempts to be supportive and participants spoke about the role of advocates and how they would prefer to be able to make their own decisions:

> *"Having work supervisors making decisions based on their beliefs about the effect of MS on performance at work was a source of concern for GH. When describing decisions about her workload, she commented, 'They worry about me working too much. It irritates me. I don't want*

> *them making decisions for me and not letting me decide for myself, like I'm a little kid and can't think for myself. They patronise me. I guess I am defensive to a point, but I cannot even let it start happening.'" – Yorkston et al. (2003) page 374*

Part of feeling supported to stay in work comes down to employers understanding the nature of MS and adjusting their expectations accordingly:

> *"I think it would be good to have somebody else who went and talked to them about it: 'what would you need'…it would help your employer, understand it better because it's coming from a professional.'" – Sweetland et al. (2007) page 1186*

This does raise the question of whether employers can undermine PwMS as having the required expertise in their own illness. Although Sweetland et al. (2007) were asking what participants wanted from a vocational rehabilitation provider, the study does highlight how there are still social barriers to negotiating reasonable adjustments with employers. For example, in the academic settings, having an advocate was found helpful in being able to make modifications at work:

> *"I did have a faculty association member at the meeting of my tenure, the university committee on tenure, because it was a problematic application. But that's not unusual because there's one there whether I had MS or not. Yes, I did get support. I spoke to the [faculty association] person who would be there at the time, admitted to him my condition, he was extremely sympathetic…to say, 'I can understand the stresses of all these things with family and now with disease and tenure and we'll be there by your side.' So he was quite supportive." – Crooks et al. (2009) page 28*

On the other hand, other studies found a very different experience where staff, such as administrators, created barriers to accommodation requests, perhaps due to false assumptions about MS:

> *"I applied for my chair to be paid for. And the woman [administrator] said, 'we don't buy furniture', and I knew this was not true because my neighbour had just…bought a standing desk through that service because she has leg problems. So…then I said, 'well, you know it would help with my fatigue', and she said, 'oh we have several people at the university with MS and they don't need anything like this.' In the end I applied for six hundred dollars' worth to pay for my furniture and they only granted me three hundred dollars and I don't know why." – Stone et al. (2013) page 162*

Theme 3: Managing Impact of MS (22 articles; Mean CASP 13)

Often when discussing its impact on their lives, PwMS personified their illness as an 'enemy' that they needed to overcome:

> *"'I don't give into it,' said a younger woman when explaining how she continued to drive, as her job required, using a patch over one eye (due to MS exacerbation)" – Salomone et al. (1998) page 75.*

And, while some felt they were managing to win their battle with MS, others described how it had not only taken away their career but mired all aspects of their life:

> *"It [Multiple Sclerosis] destroyed my career. I can no longer work. It…[also]…destroyed the most important relationship in my life. That's why I'm alone now. It's been nasty." – Salomone et al. (1998) page 74.*

Theme 3: Managing Impact of MS; Sub-theme 1: (Mental) Wellbeing (15 articles; Mean CASP 13)

With having MS, participants found they needed to make decisions about how to continue working in a way that allowed them to maintain their overall wellbeing. Unfortunately, in taking steps to manage wellbeing, other positive aspects could be impacted negatives, and many found themselves having to make a choice about what they needed most:

> *"I have to say I kind of self-distanced myself in some ways and I don't know if that was right or wrong. I find the workplace a stressful place to be and it's not that anybody here is bad or anything, but the university itself is, you know, it's always been kind of a toxic place and not for me alone…And so I have found that I've been healthier at am arm's length and so…whereas before I used to do all of my research and writing in my office, I don't any longer. And so I feel like I'm self isolated a bit and I miss that. I miss the interaction with colleagues and such." Crooks et al. (2009) page 29*

As a further example, the impact of having MS, combined with learning to cope with changes to one's identity and making changes at work, could take its toll on mental wellbeing and lead to reduced confidence:

> *"I would say, don't be so hard on yourself. I mean, looking for a job is difficult enough and I think [people with MS] put so much added pressure on ourselves because of the worker we used to be. I think it's a very difficult process psychiatrically because it can be very depressing and frustrating" – Bogenschutz et al. (2016) page 65*

Importantly, participants discussed how work could be fulfilling and beneficial to their on-going wellbeing:

> *"Some described working as therapeutic. BL commented, 'I don't think about being tired when I'm at work, my mind is too busy to think about my legs hurting. That's the best reason why people should work. You forget about the MS. If I am home, I get really depressed.'" – Johnson et al. (2004) page 203*

However, workload carried the risk of reducing wellbeing through exhausting one's resources and causing stress:

> *"CW indicated that stress once made her job as a financial consultant "enjoyable". She stated, 'There was a time that I could easily do my job to make order out of chaos. Let me at it. That is just what I enjoyed most, to organise things and whip it into shape, and leave just really happy at the end of the day.' She left her job when fatigue and cognitive changes occurred and she no longer had the resources to perform her job. She described when stress changed from enjoyable to aversive as being 'the point at which I simply did not have the energy to gather my wits about me.'" – Johnson et al. (2004) page 205*

This quote highlights how, unfortunately, a point is often reached when the symptoms of MS become a barrier to continue working, at least in one's current role.

Theme 3: Managing Impact of MS; Sub-theme 2: Symptoms (20 articles; Mean CASP 13)

A number of the articles revealed some of the impacts of the symptoms of MS on the experience of paid employment:

> *"At time a specific problem was cited as creating difficulty with work retention, such as poor vision or ataxia, which impacted on the ability to use particular equipment. For example, a 48 year-old female who had worked as a civil servant commented on her ability to use the mouse of a computer:*

> *'I would have liked to work 10 to 12 hours a week but my hand-eye coordination was too poor.'" – O'Connor et al. (2005) page 893*

The uncertainty of symptoms means that PwMS can constantly have to adjust and think about new ways to manage their MS with work:

> *"Everything that happens to you is like a learning process that you have to go through. It gets hard when symptoms occur again. When it's kind of stable you can put it to the background giving you the feeling that nothing is going on. But then you encounter new complaints, things that you've never had before and that scares me. Recently, I was really shocked when in September I suddenly didn't feel my arm anymore; that was awful." -van der Meide et al. (2017), page 4*

Many participants cited the impact of MS symptoms but the most prominent was fatigue:

> *"Fatigue may not only be profound but also unpredictable. According to DS, on some days '...fatigue means not being able to get out of bed at all. Days where physically you just can't do anything.'" – Johnson et al. (2004) page 204*

Importantly, many participants noted how, as an invisible symptom, fatigue could be hard for colleagues to accept:

> *"But look, I was just so fatigued I ended up spending weeks in bed. And even then, he rang up and told my wife, 'Tell him to get in here. There's nothing wrong with him.'" - Vickers (2012b), page 8*

The invisibility of MS meant that PwMS who did not want to disclose their illness were finding ways to manage symptoms, such as visual problems, in creative ways:

> *"I used to work as a teaching assistant quite a bit, and I'd write stuff on the board and I couldn't see it. If someone asked me… 'What does that say?' I'd have to sort of trick them into pointing me to where on the board. This was prior to [my] actually coming out with the disease. I tried to keep it secret as long as possible." - Johnson et al. (2004) page 206*

Visible symptoms of MS raised additional issues for PwMS about disclosure, as those who did not wish to disclose were unable to 'hide' their MS at work:

> *"In my job I have to -, we have to work at a computer station, pretty much, but we work with plans, drawing plans, and I have to use a scale ruler quite a lot to get the lengths and dimensions of things. And that sort of requires two hands. You've got to position the ruler and hold it down. I couldn't do it [Slight laugh]. So, I went and got a new type of ruler that would allow me to do something and I would have to write left-handed; I couldn't write. But I was trying to conceal all of that…I managed to cover it up fairly well, I thought, but of course they obviously could see something was wrong…" Vickers (2014a) page 1362*

For others MS may begin as an 'invisible' illness, and then symptoms that develop or worsen mean making changes at work that reveal signs of disability more overtly:

> *"Up to about probably five years ago I used to stand up and, uh, teach, and, uh, now I can't stand up. So, I now lecture from my…wheelchair. I think I thought that was going to be kind of a 'crossing of the Rubicon' [i.e., reaching the point of no return]" - Crooks et al. (2011), page 47*

PwMS found they had to plan carefully around their symptoms, in order to avoid the negative consequences these could pose:

> *"MV: And given the bladder problems you mentioned, is that elapsed [travel] time ever a problem?*
>
> *Sean: Ah, no. I'm very careful. I always go [to the toilet] before I leave and yes, I go very regularly now. I never leave it." Vickers (2014a), page 1362*

Theme 3: Managing Impact of MS; Sub-theme 3: Spatio-temporal Strategies (18 articles; Mean CASP 13)

Spatio-temporal strategies were discussed, such as making changes to travelling to work or using adaptive equipment. While some participants were able to make suitable adjustments, others found that barriers in the workplace environment prevented them from continuing to work:

> *"I was at a job once at [a luxury car dealership], and they got a new site…and I was so excited! We're going to go over there, and we did. It was all stairs and I couldn't stay. I tried. I always try, but it didn't work for that reason." – Bogenschutz et al. (2016) page 66*

Yorkston et al. (2003) is the first paper, in terms of publication date, to score relatively highly (above 12) on the CASP evaluation and reports mostly on the practical elements of managing MS in the workplace. Participants in this study had developed strategies to manage their work as well as allowing themselves to change how they viewed their work:

> *"RC worked as a receptionist, a job requiring her to remember many phone numbers. She had formerly prided herself on remembering this information. When she began posting lists of these numbers, she explained this strategy to her co-workers:*
>
> *"I say to them, you get to the point where you figure 'why should I make myself crazy trying to remember this?' That's why I have it on a piece of paper. Don't knock yourself out memorizing. It's here and it will always be here."" – Yorkston et al. (2003) page 377*

In a slightly later study, participants discussed how they successfully utilized even simple accommodations in order to continue working:

> *"The accommodation BL needed was simply a modification of her schedule. 'I come in early in the morning and try not to stay late. I manage the work and the work gets done. It may be on my schedule but it gets done." – Johnson et al. (2004) page 206*

There are multiple ways to complete a task and, by her employer being flexible, BL was able to continue working and maintain productivity. And in another study, one participant summarized how important flexibility was to continue working effectively:

> *"There are days where I can't tell you if I'm going to need to work from home. So I work from home on Monday and Friday, but if there's a Thursday that my leg decides not to function properly, or is 100,000,000 degrees outside…it's in your interest for me to have an unscheduled work day" – Bogenschutz et al. (2016) page 67*

However, for others, knowing what modifications they could make at work to manage the impact of their MS was not as clear:

> *"People with MS wanted advice on how to manage their performance in the workplace when the impairments associated with MS interacted with the physical environment and/or demands of the job to limit function." - Sweetland et al. (2007) page 1185*

This interlinks with what appears to be uncertainty around the term 'reasonable adjustments' and the legal rights of people with disabilities at work.

Theme 4: Labour rights (10 articles; Mean CASP 12)

Aside from managing the social, physical, and psychological impact of MS in the workplace, PwMS often find themselves struggling to navigate complex policies and procedures in order to protect their livelihood:

> *"A woman at a university with an office to assist disabled faculty ended up going on long-term disability benefits and not returning to work before retirement, but she could have arranged to work an 80 per cent load while being paid full salary. She would have preferred this arrangement over prematurely leaving her job and said: 'The personnel people, the Dean actually at that time should have known that I would be eligible for part-time disability, so I would have been paid full time…" – Stone et al. (2013), page 162*

Sub-theme 1: Awareness of legislation (5 articles; Mean CASP 13)

In the USA, the first civil rights law designed to protect people with disability from discrimination by their employers amongst other protections was passed in 1990 ("Americans with Disability Act," 1990). All the participants in O'Day's (1998) study were aware of the Americans with Disability Act (ADA) 1990 law that had just been passed:

> *"I'd say it definitely has to be better [since the ADA passed] because I know even in my own situation, even though [my employer] definitely was supportive, they knew there was the ADA law and that definitely was a factor that employers are aware of so a lot of them seem to try to be more supportive and if they know about it, will try to make accommodations." – O'Day (1998) page 144*

This is in direct contrast to Sweetland et al.'s (2007) study which suggests that many PwMS in the UK do not know what legal rights they have in work, or what is meant by 'reasonable adjustment':

> *"Most people do not know about the Disability Discrimination Act (DDA) and how it protects them." – Sweetland et al. (2007) page 1186*

Unfortunately, even when PwMS and their employers are aware of the disability at work legislation, when redress is required it is not as simple as demonstrating discrimination. Pursuing legal action can be expensive, not only financially, but time and emotionally:

> *"But to prove that was so hard […] The lawyer said, 'Maybe you'll get 30, 40 thousand dollars,' and we are talking top lawyers, 'and the stress it will cause you. Is it worth it?' And I just looked at it and I thought, 'No.'" – Vickers (2009) p263*

Sub-theme 2: Financial responsibilities (6 articles; Mean CASP 13)

PwMS had to make certain changes to their employment which reduced their financial security, which meant having to compromise on what they could afford as well as previous goals:

> *"It is also hard when you're looking at paying your bills, you know, wanting your kids to go to college and knowing that it is because you can't work that these things are difficult now. It was not the plan…When your children are asking you why can't I go to such and such school or why can't – why won't you help me more financially with college and you're saying, you know, I had wanted to. The plan was that I'd be working full-time and that that would all be going toward your college education and this and that, that's hard to tell your kids." – Coyne et al. (2015), page 251*

In addition to financial responsibilities such as keeping a home and family, the additional costs of medical expenses were a major concern for people in places where health insurance and medication had to be paid for:

> *"Now, yes, it's a necessity to pay my bills, do insurance and all that whereas before I had a couple years where I was working I didn't have insurance, and I didn't care because I wasn't sick. I was a pretty healthy person, and I didn't go to the doctor every 6 weeks or whatever. Didn't take any medication at all." – Meade et al. (2016), page 33*

The pressures associated with financial responsibilities meant that PwMS felt that making changes to their employment situation would be too precarious:

> *"I would find it scary to start a new job now. In that case, you have to start with a one-year contract. If something happens in that year…I'll lose everything. I mean, I currently have really good disability insurance. What I don't want is that everything falls apart." – (van der Meide et al. (2017), page 6*

Sub-theme 3: Accessing benefits (3 articles; Mean CASP 12)

PwMS had to consider how their access to benefits would be affected by their job because, for many, they could not afford to risk a reduction or termination of this support:

> *"Participant: Well, I had been working 40 a week, but I'm going to switch in January. When I go back, I will be working 20 a week.*
>
> *Moderator: Are you comfortable sharing with us why you're reducing your hours at work?*
>
> *Participant: I don't have a choice. In order to have Social Security Disability, I have to only make a thousand a month so I had to switch because of that." – Bogenschutz et al. (2016) page 67*

The concerns about accessing benefits were more than just income related.

> *"That's what really concerns me…that they would also take away my food stamps, they would take away my pharmacy prescriptions. So if I found a job, I'd have to find something that I could still retain my disability on, as well as my medical benefits." – O'Day (1998), page 143*

Hence, PwMS often reported that they were afraid to return to work, or felt unable to change their job, due to the difficulties they had faced with securing adequate welfare support:

> *"The doctor told her that he didn't want her to work anymore. She tried to get benefits, 'but the government says that I'm not disabled enough. They told me to get an easier job. Well the job I had was as easy as you can get.'" – Jongbloed (1998) page 195*

However, PwMS who had accessed benefits found that it meant considerable changes to their circumstances:

> *"Right now I'm on Social Security Disability and it's not great. Obviously it ends up being $35,000 a year loss from when I was working. So with some rearranging and stuff, I get by." – Bogenschutz et al. (2016), page 67*

Discussion

31 publications were found which incorporated qualitative methods to explore the experience of paid employment and MS. A thematic meta-synthesis of the combined data was conducted and 4 major themes, encompassing 11 sub-themes, were identified: *Social attitudes (Stigma of MS, Identity, Work norms), Level of support*

(Help from others, Advocacy), *Managing impact of MS (Mental wellbeing, Symptoms, Spatio-temporal strategies)* and *Labour Rights (Knowledge of legislation, Financial responsibilities, Accessing benefits)*. These 4 major themes can be fit to the hierarchical features of the socio-ecological model, through micro-, meso- and macro- levels (see Figure 2.3).

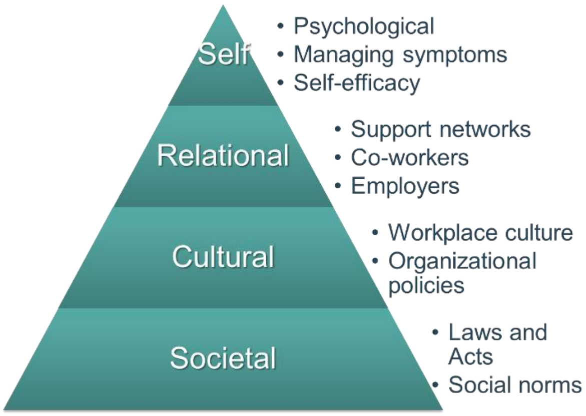

Figure 2.2 - Themes in relation to the Socio-ecological model

The three most prominent sub-themes of the meta-synthesis of the findings of the extant literature found in the SRR are: *Stigma of MS*, *Advocacy*, and *(Managing) Symptoms*, which appeared in 21, 20 and 20 papers respectively. *Spatio-temporal strategies* was also a common sub-theme which appeared in 18 papers while *Mental wellbeing* and *Identity* appeared in 15 and 12 papers respectively. *Labour rights* (10 articles) was less prominent, with *Accessing benefits* appearing in only 3 of the 31 articles. The papers which discussed access to disability welfare included two from USA and one in Canada. When considering the programmatic structures for accessing medical care in the USA, it is not unexpected that this would be a key concern for PwMS living in that country.

In fact, it is worth noting at this point the originating countries of the articles included in this review. 10 of these articles were from research conducted in Australia, while a further 9 were based in the USA. Five were conducted in Canada, two in The Netherlands and one in Ireland. Only 4 articles originated from the UK. Whilst it is interesting to compare the common themes that occur globally in the experiences surrounding employment and MS, this review also highlights the limited qualitative work exploring the specific experiences of managing continued employment within the UK systems. The first UK based study, McFadden et al. (2012), utilized content analysis to understand key factors in order to develop a quantitative scale to measure work instability. Whilst an important measurement tool, this study does not explore in detail the complex experiences of paid employment and MS. The second, Jellie et al. (2014), seeks to examine the specific impact of a vocational rehabilitation intervention.

Whilst the papers which covered the sub-theme, *Stigma of MS* averaged a CASP score of 12, 15 of the 21 articles had a score of 12 or above showing that, for the most part, these were relatively good quality papers. Stigmatisation of MS was an immediately prominent theme for this review and could have an impact for PwMS on psychological wellbeing as well as presenting physical barriers to work. For example, in O'Connor et al. (2005), one participant speaks about being unable to return to work as there were steps leading to the office, preventing access with their wheelchair. Although the Disabilities Discrimination Act was introduced in 1995 and did specify that any physical feature of occupational premises should not "*place the disabled person concerned at a substantial disadvantage in comparison with persons who are not disabled*" ("Disabilities Discrimination Act," 1995), the pressure on many businesses to adhere did not appear to be put into action until October 2004, following the DDA 1995 (Amendment) Regulations 2003. Unfortunately, the case law surrounding this legislation, which has since been replaced for the most part by the Equality Act 2010, has inherent complexities. For example, the Planning (Listed Buildings and Conservation Areas) Act 1990 which limits alterations to be made to certain heritage buildings is in direct contradiction to the requirements of service providers to make such access adjustments. It is for this reason that the legislation is deliberately vague, bringing to light the importance society places on heritage versus equality. Oftentimes, stigmatisation did not appear to be an overt discriminatory attitude, but rather a lack of knowledge or simply unawareness of the potential barriers for PwMS in work, due to this not being intrinsically visible to colleagues or employers.

Society in the developed west in the 21st century has a strong emphasis on the value of being a worker and contributing to society through paid employment. Being in a position of no longer having a worker role, or job insecurity, can be detrimental to a person's sense of self-worth. Societal norms and ablest norms in particular are detrimental, because they fail to see 'outside the box' of these workplace social constructs to which people feel they must adhere. Being prepared to take a flexible approach to how work is completed can raise the benefits to employers such that they are able to keep a valuable employee who can continue to be productive. To this effect, having an employer or person with some authority that advocated for them to stay in work, PwMS faced considerably less barriers to factors such as securing accommodations as well as feeling valued as an employee.

For many PwMS, spatio-temporal strategies not related to the needs of the job itself were instrumental barriers to job retention. Changing how they viewed their work or utilizing strategies to manage the parameters of their workplace helped PwMS to keep working. However, the accommodations available were not always clear to PwMS or their employers. Some employers lacked understanding of the individualistic impact MS can have, thus although well-meaning in their intent, would simply curtail an employee's responsibilities, rather than adjusting the role adequately. This could cause considerable frustration for PwMS who wanted to continue working but found that their work no longer gave them the same fulfilment it had.

This review also highlights the uncertainty of a disease such as MS. Although PwMS can utilize strategies to reduce the likelihood of symptom impact, the unpredictability makes it a challenge to plan ahead. This uncertainty makes it vital that PwMS can take steps to maintain wellbeing. Stress and insufficient coping strategies were important factors that could lead to leaving work earlier than desired, whereas having a support network to reduce psychological burden was a positive factor that helped PwMS to stay in work. Stress and anxiety are high risk factors for PwMS, not just as a result of adjusting to changes in physical function, but also due to the financial insecurity of reducing or stopping work. In addition to this, navigating the complex welfare systems to secure adequate benefits could be particularly stressful. PwMS find themselves having to make compromises in order to meet their families' needs, as well as additional healthcare costs.

Many of the papers focused on a particular aspect of the employment experience, for example provision of vocational rehabilitation services, or the specific experiences of women with MS. The studies had a strong representation of people in the earlier stages of their MS, with less information about the experiences of progressive MS courses. None of the papers reported the experiences of relevant employers or healthcare providers, who may have provided additional contextual information to the social constructs that may be emerging.

Seven of the articles reported using content analysis. This is an extremely useful method for examining the key themes that are important for PwMS in employment, however, in order to understand the complex interrelationships between the self, the disease and the social constructs at play, further research needs to take an in-depth analysis approach. Fourteen of the articles collected data using convenience sampling, compared with only 5 reporting purposive sampling techniques. Although the concept of 'data saturation' is not dependant on purposive sampling, it contributes to collection of richer data and aids a more in-depth analysis in line with the specific aims of the research.

5 of the 31 papers included only female participants with two of these targeting their study specifically to the experiences of women with MS in the workplace (Cahill et al., 2010; Dyck & Jongbloed, 2000). Both studies found that identity played an important role for women with MS in the workplace as women tried to balance the impact of their MS both within the complexities of workplace culture and their personal roles, for example, within the family structure. Other studies touched on the specific barriers women face when managing these divided roles, for example in O'Day (1998), one participant states "*I could not handle that work load and being a mother"* (p.141).

Eagly (1987) describes the division of labour according to gender roles, in that socially, women are expected to perform family caregiving roles whilst males tend to be in the positions of authority in the workplace. With more recent social shifts, women are increasingly becoming the primary "breadwinners" and following careers. However, they have achieved this whilst maintaining house-care and family duties. This said, the social construct of the 'ideal worker', which as we have seen, plays a negative role in providing flexible conditions or policies for workers with disability, also falls short when attempting to balance paid employment with family responsibilities (Acker, 1990). The construct is built on the out-dated concept of the "male worker", unrestricted by childcare duties or homemaking. Bowles and Babcock (2012) concluded that women face greater challenges in the workplace when negotiating pay increases as well as experiencing more negative backlash due to gender stereotypes. Such findings could potentially be transferrable when considering women's' experience of negotiating workplace adjustments. Gaining an understanding of detrimental gender roles in the workplace could help in determining how best to minimize the combined impact of this with MS at work.

Gender inequalities in the workplace continue to be prominent, with women continuing to face barriers to career progression not seen by their male counterparts (Stephens & Levine, 2011). Stephens and Levine (2011) determine that although gender inequality in the workplace persists, society often fails to recognise the structural barriers that prevent women from meeting their potential in the workplace. Instead, it is commonly assumed that women are leaving work by individual choice. This 'choice framework' bears resemblance to the 'Clayton's choice' concept described by Vickers (2014). One paper did include a male only sample, reporting on a single case study of shame experiences in the workplace (Vickers et al, 2012b). Although this study did not set out to explore the specific experiences of men with MS, it is interesting to consider the role of shame and its impact on the discourse between disability and masculine ideology.

Being an often-invisible condition, many employees with MS face making a decision as to whether or not to disclose their diagnosis at work. This decision to can be a complex and highly individualistic process which can be shaped by level of support (Kirk-Brown, Van, Simmons, Bourne, & Cooper, 2014), sense of identity (Dyck & Jongbloed, 2000), ability to manage symptoms (Raggi et al., 2015) and uncertainties around legislative rights (O'Day, 1998). Even when PwMS are aware that they have rights at work, many are not aware of how these apply or the schemes in place such as the DWP Taxi to Work scheme (Jellie et al., 2014). In addition, employers may not be aware of their responsibilities or how they can utilize reasonable adjustments appropriately (Bogenschutz et al., 2016). Even when MS is disclosed, PwMS are not always sure what accommodations they require or how to request these, particularly those related to mental health (Frndak et al., 2015). Worryingly, accommodations that involve schedule adjustments or expensive devices are less likely to be granted (Rumrill, Fraser, & Johnson, 2013). Some PwMS feel pressured to disclose, either to try and "prepare" their employers, or due to increased questioning from colleagues (Reed et al., 2017). PwMS may also delay disclosure until it is necessary, for example, due to worsening symptoms or increased doctors' appointments. One participant in a study Vickers (2014a) spoke about how it became difficult to hide symptoms: *"I couldn't write. But I was trying to conceal all of that…I managed to cover it up fairly well, I thought, but of course they obviously could see something was wrong…" (page 1362).*

Unfortunately, delaying disclosure may result in it becoming too late to introduce effective management strategies to continue working (Simmons, Tribe, & McDonald, 2010). Individuals who feel that their work environment is 'psychologically safe' are more likely to disclose their MS (Kirk-Brown & Van Dijk, 2014). Psychologically safe environments are those in which the employee feels trusted and respected and able to take interpersonal risks or discuss personal issues. Consequently, PwMS who do disclose tend to stay in work longer despite physical decline (Kirk-Brown, Van Dijk, Simmons, Bourne, & Cooper, 2014). Disclosure can lead to increased work accommodations which may help the individual to continue working.

This review has both strengths and limitations to consider. A systematic search strategy was developed and cross-checked with both a librarian and academic supervisor and used across relevant databases for consistency. This search strategy is outlined in the appendices for transparency. There was no limitation set for date of publication, as it was deemed unlikely that literature in this area would go back much further than 30 years and so this review should make available the full chronicle of English-language research on this topic. That said, the unavailability of resources for translation services meant that the search was limited to English-language publications only, and so important findings from alternative languages may have been missed. Quality analysis of the final literature set (e.g., CASP scoring) was completed independently on a selected sample of papers by two researchers and findings discussed to determine validity and consistency in use of the scoring tool. This process was recorded and is presented in the appendices for accountability. Although thematic analysis was conducted by a single researcher, findings were discussed and reviewed with the academic supervisor to encourage reflexivity, a process which can help to disband potential bias from subjectivity within qualitative research (Gough & Madill, 2012).

In summary, this SRR and thematic meta-synthesis highlights that the experiences of working with MS that contribute to successful job retention or employment barriers are complex and occur at multiple levels. At an individual level, PwMS must adjust to and find strategies to manage their changing physical and cognitive functions, whilst simultaneously employing coping strategies to manage their wellbeing. PwMS also find that the help and support of not just their family and friends, but employers and colleagues, has an important role to play. Employers that act as advocates for PwMS to continue working pave the way for easier access to spatio-temporal strategies, as well as offering psychological encouragement. In contrast, employers or colleagues that lack understanding can present significant barriers to PwMS through discrimination and other forms of stigmatisation, including bullying. On a broader scale, the social norms of how work is viewed can make staying in work a losing battle for PwMS, who are unable to adhere to 'ablest' constructs.

As barriers and facilitators have been shown to occur at all levels of the socio-economic model (i.e., individual, interpersonal, cultural and societal), effective strategies to improve job retention for PwMS has a potential footing at each of these levels. However, the locus at which employers and PwMS can work together to improve employment experiences seems most pertinent at organisational level. Strategies implemented at this level could help to build a psychologically safe work environment, in which PwMS are empowered to access support for wellbeing as well as spatio-temporal management strategies. Encouraging a diversity-centric workplace culture, for example via educational programmes or implementation of relevant policies, could also serve as a catalyst to reduce stigmatisation faced by people with disabilities in work. Such programmes can also help to improve awareness and understanding of legislative matters both for PwMS and their employers and could ultimately reduce the stress and confusion in navigating relevant welfare systems.

Addendum

Since the conduction of the above systematic research review, an updated search was completed. The search was completed again for literature between May 2017 and September 2020. After eyeballing, total hit count was 276; after abstract screening, the hit count was reduced to 40. A final total of 8 articles met the search criteria. Of note, five of these articles were published by first author Lavanya Vijayasingham, who discloses a diagnosis of MS. In her 2018 article (#3 in Table 2.7), Vijayasingham provides an in-depth heartful narrative of her personal journey in relation to work life, since her diagnosis in 2009. The events following her diagnosis became a catalyst to her redefining her work goals and consequently pursuing a qualitative PhD on the topic of MS.

There has been a notable increase in interest on the topic of employment and MS in recent years. Despite the initial systematic search spanning over three decades, the abstract screen saw just 31 articles retained. Whereas, this recent search covered a period of just over 3 years, and retrieved 40 articles relevant to the topic of employent and MS.

Despite recent revisions to the Critical Appraisal Skills Programme (CASP) measure (2018), I decided to re-use the adapted 2013 version to make the scores comparable with the original review. Quality of the articles was high, with CASP scores ranging from 12 – 16. As with the original review, articles most commonly fell down on consideration of the relationship between the researcher and the participant. Research stemmed from the US, UK, Malaysia and South Africa. The two papers by Thompson et al. (2019a; 2019b) utilized data from the same research study. Likewise, two of the papers first authored by Vijayasingham (2017; 2020) were from the same participant data. Thus, the 8 articles covered a total of 6 qualitative or mixed-methods research studies.

Unfortunately, papers by Roessler, Rumrill, and Timblin (2017) and Lee, Ditchman, Thomas, and Tsen (2019) could not be accessed, despite attempts through multiple accession routes, and a full-text request via Researchgate. Therefore, CASP scores could not be assessed, although information about the studies was derived from the abstracts. A request via Interlibrary loans will be made so that these articles can be included in an in-depth, up-to-date systematic review; this will form the first peer-reviewed publication from this work to be submitted.

The first accessible article (Vijayasingham, Jogulu, & Allotey, 2017), sees similar themes as identified in Table 2.6 (see page 49); identity is presented as life roles and work norms are considered when re-evaluating how work is managed by PwMS. The article discusses the role of help and support from others outside of work as well as continuing to provide support (e.g., as family caregivers). A key additional insight from this paper is coping strategies and psychosocial management; how PwMS make work-decisions based on their future goals and fears living with MS as well as managing stress to reduce psychosomatic impact from MS. This is likely to be linked with uncertainty of MS. Vijayasingham et al. (2017) also outline how PwMS attempt to balance work demands with health, with some deprioritising high work demands in order to achieve a better work-life balance. Kruger and Coetzee (2019) also found that PwMS many reprioritise their goals and hold fears about future progression with MS and what it could mean for work. Goal-adjustment could also be linked to roles outside of work, such as family commitments; similar concepts were discussed by Vijayasingham et al. (2017). Key themes in this article included *Coping strategies* and *Disclosure experiences*. Kruger found that participants may disclose to gain understanding or to foster good interpersonal relationships in the workplace.

The two papers by Thompson, Ford, Stroud, and Madill (2019a; 2019b) also consider coping and strategies for managing MS alongside work demands; in the first paper, two distinct chronotypes are recognised through participant narratives. Where the ‘hare’ (or *unsustainable epic*) chronotype uses condensed time, the slow-and-steady ‘tortoise’ (or *temporary idyll*) focuses on condensed space. These chronotypes link into discussions in Vijayasingham’s (2017) article, in which PwMS consider the distinct poles of continuing high work demand at the risk of illness failure (*Hard Work as Risk to Illness Future*), versus finding a steadier-paced illness-work-life balance (*Pursuit of Illness-Work-Life-Balance*). Thompson et al. (2019a) also identify the role of the line manager and potential impact of the employee-employer exchange relationship. This finding especially calls for more in-depth research at the organisational (meso-) level, to understand how organisational exchanges may help or hinder PwMS to stay in work. Such research is further justified by the findings by Vijayasingham, Jogulu, & Allotey (2020); PwMS experience a reduced agency in decisions around work transitions. These *socio-structural constraints* can act as barriers to job satisfaction and progression for PwMS and are often related to work norms.

Thompson et al. (2019b) use a form of dialogical and conversational analysis to understand the ways in which PwMS re-tell their workplace experiences; the use of parody as a coping strategy is an interesting insight. The use of humour as a coping strategy has been explored previously by Strober, Chiaravalloti, and DeLuca (2018) and would be an interesting area for further research.

These additional papers indicate that research on the subject of MS and work is moving closer to understanding the psychological and social barriers to employment for PwMS; psycho-social management strategies, the interplay between managing work-life and home-life and the role of the managerial exchange relationship are all important factors that deserve further exploration in research.

Table 2.7 – Data extraction table 2017-2020

#	Author(s), Year Country CASP Score	Aim	Data collection Data analysis Sampling Technique	Sample	Key themes/findings
1	Roessler et al. (2017) USA	To explore the subjective experiences of people with MS regarding employment barriers.	Focus groups	20 people with MS 27 MS service providers	Understanding the provisions of the Affordable Care Act, On-the-job accommodations and the Americans with Disabilities Act, Reassignment as a job retention strategy Disclosure of disability.
2	Vijayasingham et al. (2017) Malaysia **12**	To draw attention to how individuals perceive, imagine, and negotiate the long-term course of work	Hermeneutic phenomenology Personal introductions through key informants and via social media platforms of the Multiple Sclerosis Society of Malaysia committee In-depth interviews, followed up through intermittent text-based communications (WhatsApp) and digital images with captions from participants, so they could depict and represent important aspects of their lives and work with MS.	10 “white collar workers” with MS white-collar” workers with MS (based on the International Labour Organisation’s ISCO-08 classification of major workgroups)	Prognosis: The Field of Worst-Case and Best-Case Futures. Hard Work and Stress as Risk to Illness Future The MS Prompt for Lifestyle Change and the Pursuit of Illness-Work-Life Balance. The Caregiving and Care-Receiving Patient: The Influence of Life Roles and Family Dynamics
3	Vijayasingham (2018) Malaysia **14**	To portray the longitudinal journey of negotiating work after a diagnosis of MS	Autoethnography through automythology (“The hero’s journey” or monomyth framework)	1 researcher diagnosed with MS	“The hero’s journey” narrative, outlined as: (Not being able to) Work right: separation, moral failure, a threat to the Existing, Reciprocal blocks Looking for the right (type of work and engagements): Initiation, moral repurposing, the clash of Old and New, reciprocal review Right work: Return, moral reinstating, New Normal, positive reciprocity.
4	Kruger and Coetzee (2019) South Africa **15**	To explore how employed PwMS experience their disorder in the South African working environment	exploratory qualitative research design (Bless, Higson-Smith, & Kagee, 2006) purposive sampling Semi-structured interviews with open-ended questions	7 white South African PwMS employed in an office-based job.	Physical restrictions, person-environment interaction, MS symptoms, self-assessment (patient perspective)
5	Lee et al. (2019)	To investigate the experience of microaggressions in the	Focus Groups Content analysis	29 adults with MS across 8 focus groups	Pathologizing, assumption of disability status, second-class, lack of awareness, social distance, and denial.

		workplace among individuals with multiple sclerosis			Perceived stress was associated with micro-aggressions; exacerbated the negative impact of uncertainty related to symptoms and job security.
6	Thompson et al. (2019a) UK **14**	Two key RQs: 'How does MS affect people's sense of self and motivation to remain in paid employment?' and 'Can we identify patterns of chronotope use in the participants' narratives?'	Focus groups: unstructured, with a broad topic guide Opportunity sampling Dialogical analysis (Sullivan, 2012)	20 PwMS employed for at least 2 years across 3 focus groups	Unsustainable epic Temporary Idyll Managerial discretion
7	Thompson et al. (2019b) UK **16**	To explore further the potential of DA through analysing focus group interviews with PwMS in paid employment.	Focus groups: unstructured, with a broad topic guide Opportunity sampling Conversational Analysis (Jefferson, 1983) and Dialogical Analysis (Sullivan, 2012)	20 PwMS employed for at least 2 years across 3 focus groups	Oh-prefaced direct reported speech (OPDRS) as a strategy to create parody in response to managers who misperceive MS Self-evidency by Others in the Workplace Through casualizing Self-evidency by Others in the Workplace Through News Receipts
8	Vijayasingham et al. (2020) Malaysia **15**	To compare the lived experiences of work for PwMS, with emphasis on how personal career resources and structural level dyanamics influence how individuals negotiate work transitions	Purposive sampling Conversational, semi-structured interviews followed up through intermittent text-based communications (WhatsApp) Joint hermeneutic phenomenological and constructivist grounded theory approach (Charmaz, 2009; Van Manen, 2016)	10 PwMS in employment, intending to continue employment, with no concomitant cognitive or severe mental health symptoms	Disruption, disengagement and duress, agentic adaptation and volitional career redirection. Reasons for change: involuntary, semi-voluntary and voluntary Exploration and opportunities: socio-structural constraints, positive anecdotes and resources New role: trial and adaptability, engagement and maintenance.

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Chapter 3: Methodology

The Researcher

The semi-structured qualitative interview forms a primary component of the method for this study therefore data collection and interpretation occur within the context of my own frame of reference. Thus, it is important to note some information about myself, as the researcher, and how my own experiences may contribute to the findings of this research in terms of my reasons for wanting to conduct this work, how I will approach interviewing, and what assumptions may infiltrate my analysis. At the time of starting this project, I am a 26-year-old first year PhD candidate, Caucasian and from a middle-class socio-economic background. These factors provide me social privilege in ways that may make me naive to the barriers that marginalised groups face generally, in the workplace, and in participating in research.

I do not have MS or, to my knowledge, any autoimmune disorder. In this respect, I am an ‘outsider’ to the population of interest in this study. Instead, I approach this research with a deep-rooted captivation with learning about people and their lives and I hope this curiosity will allow me to delve deeply during the interviews as I try to understand experiences to which I am completely naïve.

I can however share an ‘insider’ experience of being in paid employment; I have historically worked in a range of employment positions, such as white-collar work, as well as hospitality roles. I am a woman in work, meaning that I have either experienced or been distinctly conscious of certain inequalities and barriers to work women face. While this does not necessarily give me comparable knowledge to the barriers faced by PwMS, it helps me to keep a sympathetic approach in trying to understand such barriers.

My interest in neurological disorders began when I studied Psychology and Neuroscience as an undergraduate. After graduating, and following a series of fortunate opportunities, I began working as a Clinical Trials Assistant and took a prominent role in a study on the psychological determinants of job retention in MS. This study made me want to understand more about the challenges PwMS face at work, as well as sparking a real passion for the potential benefits this research might have in helping PwMS who want to continue meaningful employment. While my background in research related to MS and employment offers me the benefit of existing links to relevant groups, including PwMS and HCPs, it brings with it the potential for pre-conceptualisations relating to this research area.

I place value in the benefits of working at the individual and societal levels. If I did not, I may not be looking at this research question. However, I must try to keep in mind that others may not share the same personal constructs around work as I do.

Method of Study Recruitment: Purposive Sampling

Sample and Recruitment

This study has three data sets: Data sets 1a and 1b comprise PwMS; data set 2 employers; and data set 3 healthcare professionals. Expected sample size of approximately 6-8 participants per data set should be able to provide data saturation without creating excessive workload. This is an approximate total of 30 participants in the study. Exclusion criteria will comprise: those who do not speak fluent English; those lacking capacity to consent for themselves; those unable/unwilling to provide the contact details for their registered GP or health practitioner (data set 1a and 1b only).

Data sets 1a & 1b: PwMS who (a) are currently in work or (b) have recently left work (n~16)

I will include a purposefully diverse range of participants attempting a balance over these two data sets for:

- Gender
- Age 18-66 years
- Relapsing-remitting, primary and secondary progressive MS
- Diagnostic histories (newly diagnosed vs diagnosed for more than 8 years)
- Range of occupational settings/backgrounds
- Private (including self-employed) and public sectors
- Type of employment (white, blue, pink collar)
- Small employers (<50), medium employers (50>249) and large businesses (>250), as defined by the UK Department for Business Innovation and Skills (Statistical Release 2015).

More specifically, the inclusion criteria will include for:

  - *Data Set 1a*: In paid employment without significant gaps for a minimum of 2 years
  - *Data Set 1b*: History of paid employment which lasted a minimum of 2 years and employment which ended within the last 12 months.

Data set 2: Health professionals who are regularly responsible for people with MS (n~8)

I will aim to include:

- Occupational Therapists
- Neurologists
- Physiotherapists
- Specialist Nurses

More specifically, the inclusion criteria will include:

  - Age 18+ years
  - In a paid healthcare or related profession for a minimum of 2 years
  - Relevant working experience with people with Multiple Sclerosis.

Data set 3: Employer representatives (n~6)

I will aim to include:

- Large public sector employer (e.g., NHS and City Council)
- Small/medium public sector employer
- Large private business
- Medium private business
- Small private business.

More specifically, the inclusion criteria will include:

  - Age 18+ years
  - In a paid management or supervisory position for a minimum of 2 years
  - Working experience with managing people with Multiple Sclerosis.

Recruitment

Sampling will be purposive in order to provide maximum saturation of data for various demographic groups. Qualitative technique is built on rich data from samples of conscientiously chosen participants. For data sets 1a and 1b, potential participants will be identified by a health provider before or during specialist MS clinics in Leeds. There is also a register at the Leeds Neurology Research office of MS patients who are interested in research from which individuals will be selected for contact. The researcher will also be in contact with relevant charities who may be able to advertise this study and refer PwMS to the study. For data set 2, current connections at the Leeds Teaching Hospitals NHS Trust will be utilized to recruit health professionals from various occupational backgrounds as well as using publicly available information online if needed to identify individuals to contact. For data set 3, Human Resources departments of companies will be approached using publicly available contact information and then asked to put forward managers within the company who have experience of PwMS. Participants from all data sets will be asked to recommend relevant companies or employers if they feel comfortable to do so. Adverts will also be placed in relevant newsletters and through social media platforms such as twitter.

Potential participants who may be interested in taking part will be approached by the researcher by e-mail, telephone, post, face-to-face or through current networks as appropriate and a participant information sheet sent to people who indicate an interest in taking part in the study. The information sheet and consent form also will be made available online on the researcher’s academia.edu page. Importantly, the information sheet provides a link to an online eligibility questionnaire hosted on Bristol Online Surveys (Appendix B.1). This eligibility questionnaire is designed to route each participant through an appropriate pathway of questions based on the data set to which they belong (Appendix B.2).

Informed Consent

Informed consent will be obtained following provision of an ethically approved information sheet, prior notice of the condition of consent through a written consent form (available in hard copy and online on the researcher's academia.edu page) and providing time to ask and have any questions clarified. Eligible participants will be contacted by the researcher to discuss consent prior to interview and verbal consent – as recommended by the ethics panel - will be audio-recorded at the beginning of the interview. During this process, all participants will be made aware that they can withdraw their material up to one month after interview – again as recommended by the ethics panel.

Method of data analysis: Critical Grounded Theory

The material generated and collected in this study will be analysed using Critical Grounded Theory (CGT: (Belfrage & Hauf, 2015)). CGT was developed to address a need for qualitative work to be able to investigate the meaning-making of participants but also the social context in which these discourses are meaningful. Hence, CGT takes elements from Discourse Analysis and Grounded Theory methodologies.

Hauf (2016) discusses the benefits of Critical Discourse Analysis to move further than simple linguistic exploration but also notes that the method is limited in the extent to which it accounts for the wider context of social practices. Jäger and Maier (2009) offer a potential solution to this in Dispositive Analysis in which the activities of the participant are observed, described, and then the meaning of these activities investigated through interviews. However, Hauf (2016) argues that Jäger and Maier have yet to provide a clear method for applying this approach practically. In order to address this shortfall, Belfrage and Hauf (2015) turned to Grounded Theory methodology to explore if it could be combined with a critical realist approach, to investigate the meaning-making as well as social context.

Grounded Theory emerged from the works of Glaser and Strauss in the 1960s when qualitative methods in the social sciences were considered overly subjective and merely as preliminary research, for example to fine-tune survey questions. Glaser and Strauss were pioneers in challenging these assumptions with their book 'The Discovery of Grounded Theory' (1967) which provided a systematic guide for developing theory from qualitative data. Although Glaser and Strauss made qualitative analysis methods accessible to the novice researcher, subsequently they took Grounded Theory in different directions. While Glaser continued to work to the same fundamental empirical analytic style shaped by the data, Strauss, alongside Corbin (e.g.1990), has favoured a verificational approach which has been critiqued by as idea- rather than data-led. And, ironically, by the 1990s, Grounded Theory was becoming known for being proscriptive and overly complex procedurally.

Although Sum and Jessop (2013) reject grounded theory as ‘naïve’ in its attempt to approach the data without prior theoretical conceptualisations, more recent contributions have increasingly recognised the influence of our prior assumptions as well as moving the approach toward constructionism. Methodological developments by Charmaz (2006) and Clarke (2003) allowed Grounded Theory to become more critical, recognising the usefulness of ‘pre-concepts’, and finally acknowledging that social reality is multi-faceted and may involve a complex interaction between lived experience and social constructs. Moreover, these authors agree that the basic procedures of Grounded Theory can be applied as the starting steps of the research process and be combined with other approaches.

Charmaz pioneered the benefits to a constructivist approach to Grounded Theory, with her book ‘Constructing Grounded Theory’ (2006) outlining how this methodology could be valid and useful in understanding the constructs that lead to particular interactions and theories. Although Strauss and Corbin had cautiously recognised the benefits of having pre-conceptualisations in order to recognise constructs within the data, it was Charmaz (2006) and Clarke (2003) that pushed forward with a reliable system for conducting Grounded Theory in this manner.

As realism, which stipulates that knowledge is external to our interpretations, and constructionist theories, that mechanisms are a result of our meaning-making, take on more radical divergences in the early 21st century (Fairclough, 2005), a third option begins to emerge: critical realism. Critical realism recognises that, whilst external truths can exist, our interaction with them may influence the reality we experience (Oliver, 2011).

Although Critical Realism was developed by Roy Bhasker (2010), it was Oliver who first proposed that this framework could work effectively in Grounded Theory methodology. With a background in Social Work, Oliver found that the interweaving aspects of individual and social interaction that critical realism allows, this brought Grounded Theory as a relevant process for studying Social Work.

Classic Grounded Theory suffers from its inductive approach, thus limiting it to the cases on which it is performed. This lack of generalisability in the method has prevented it from being useful to a wider theory development for social problems. However, as Oliver’s critical realist approach brings an excellent balance of empirical evidence with meaning-making approaches of constructivism, she also introduces a retroductive paradigm under which theories can be developed. Retroduction, much like abduction, focuses on the evidence emerging in the data and looks at the possible explanations for these phenomena. The key difference between these two types of theory development is that, whilst abduction explores all possible explanations that could lead to a particular result, retroduction is specific in asking: “What has to be true for this to be the case?”

In attending to both social constructs as well as individual action, critical realist grounded theory is an extremely relevant approach for gaining insight to the experience of Multiple Sclerosis in the context of paid employment.

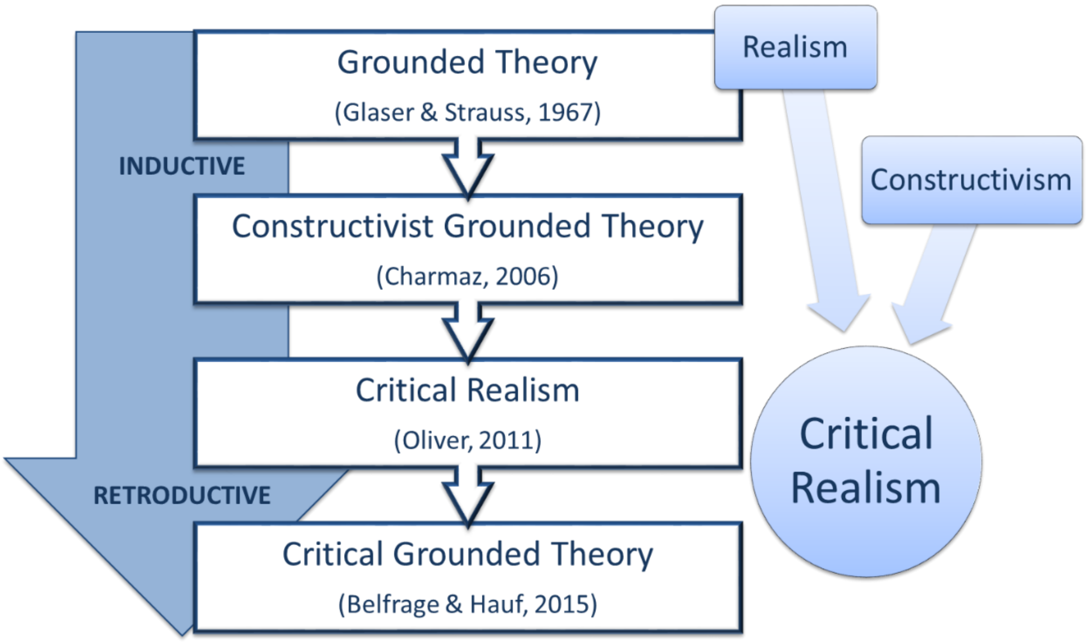

Figure 3.1 – The development and epistemology of Critical Grounded Theory

As the most recent iteration, Critical Grounded Theory builds its foundations from critical realism, such as that described by Oliver (2011). This methodological approach incorporates retroduction, by which the researcher explores possible themes, retrospectively, to explain the emergent phenomena. Pre-existing theories, either those which are making meaning of experiences, or scientific theories, are drawn upon to provide a practical explanation for empirical evidence from data collection. Thus, allowing the methodology to move away from the blinkered limitations of positivism, or verification methods, whilst also accepting that it is simply not practical or genuine to attempt to approach observations without acknowledging our own internal constructs. CGT builds further on the critical realist approach in stating that the researcher "*sees herself not as a disinterested observer but as an active member of a society ridden with social antagonisms and relations of exploitation, domination and exclusion, the explanation of which is a precondition for changing them*" (Belfrage & Hauf, 2016, p. 9). In actively exploring critical knowledge and drawing upon prior conceptualisations to recognise the constructs that may contribute to a social problem, CGT enables the researcher to understand and work to resolve these, rather than simply deciphering what the data demonstrates. This makes CGT an excellent method of analysis for the present research.

That is, my starting point is that understanding what helps or hinders PwMS who would like to stay in paid work must involve both exploring the lived experience of the key people involved but also the micro-, meso- and macro-contexts in which people – particularly people with disabilities – live and work.

Belfrage and Hauf (2015) describe the process of using CGT in practical research. The process involves recognising our own conceptualisations and theories of society and allowing these to act a starting point for the ‘social problem’ we are trying to understand, but then moving forward into a more critical analysis. Hence, first, the researcher begins with an acknowledgement of pre-concepts and theories, which are referred to as “soft hypotheses”. These are developed from an initial phase of reviewing the literature, as well as relevant media and policy documents. So, for example, for the current project, I began this initial conceptualising by conducting a systematic research review of the existing literature, as well as consulting legislation documents relevant to employment with MS (for example, the Equality Act 2010). Second, the researcher then uses these pre-concepts and soft hypotheses to inform data collection. Third, the pre-concepts are evolved in light of the empirical data so that understandings are grounded in participants’ lived experiences as well as the existing knowledges and theories.

Semi-structured interviews are well suited to CGT. First, the interview schedules have been informed by my systematic research review. Second, interviewing will be interspersed with analysis such that later interviews will be informed by the developing CGT of earlier interviews alongside analysis of policy documents from the participants’ employers. Moreover, the interview schedules can be modified to allow for emerging theories to be explored in more detail. It is likely that data sets 1a and 1b will be integrated with all 16 interviews analysed together while paying attention to the original group in which the participant sits. As analysis develops, it will become clearer the extent to which the analysis of data sets 2 and 3 can be integrated with the analysis of the data from PwMS or kept separate. Finally, the analyses and a systematic research review of the literature will be integrated to provide an evidence-based conceptualisation of what interventions might be effective in facilitating job retention in MS. This process is visualised in the figures below, in what Belrage and Hauf refer to at the “retroductive spiral” (Figures 3.2 and 3.3).

Inherent to the nature of Critical Realism, Critical Grounded Theory recognises that true “theoretical saturation” cannot be reached. This is due to the wavering nature of social constructs, which will inevitably move past the original theories that emerged during a particular time of study. However, once theories have been developed and refined within the retroductive spiral of CGT, this is informative of the social problem in question at that given point and provides a useful starting point for future researchers to adapt these theories gradually in line with the changing social systems.

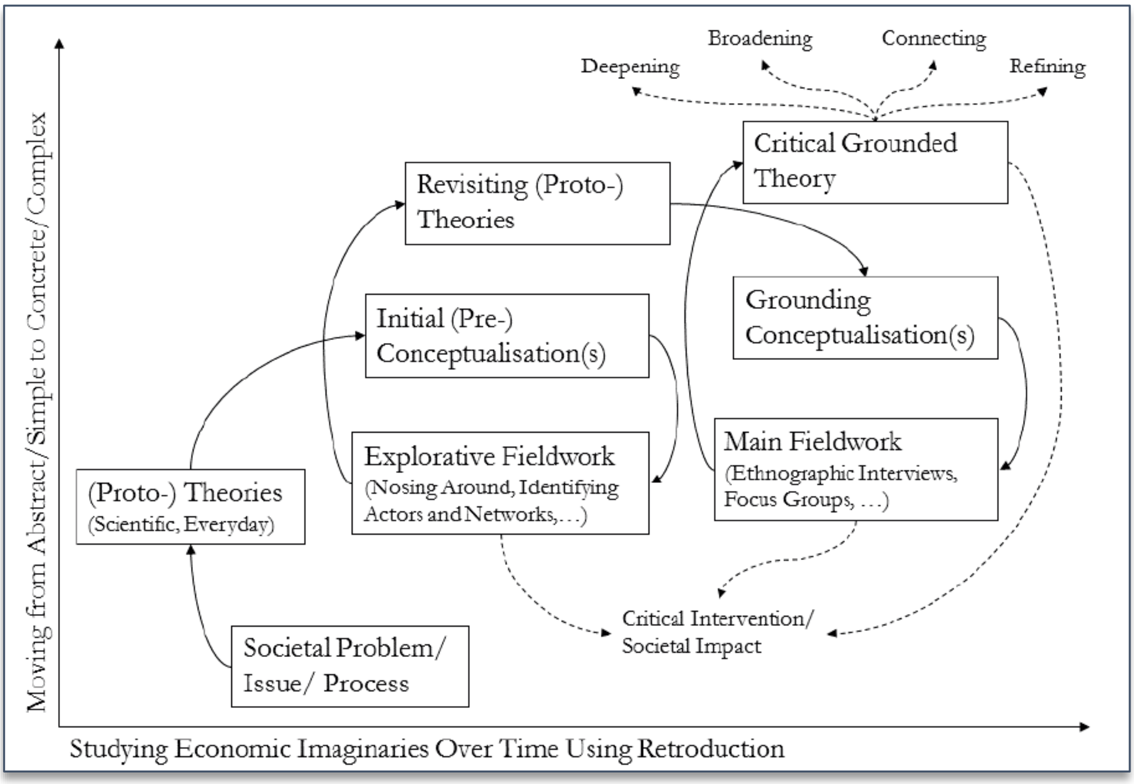

Figure 3.2 - The retroductive research process of CGT (Belfrage & Hauf, 2015)

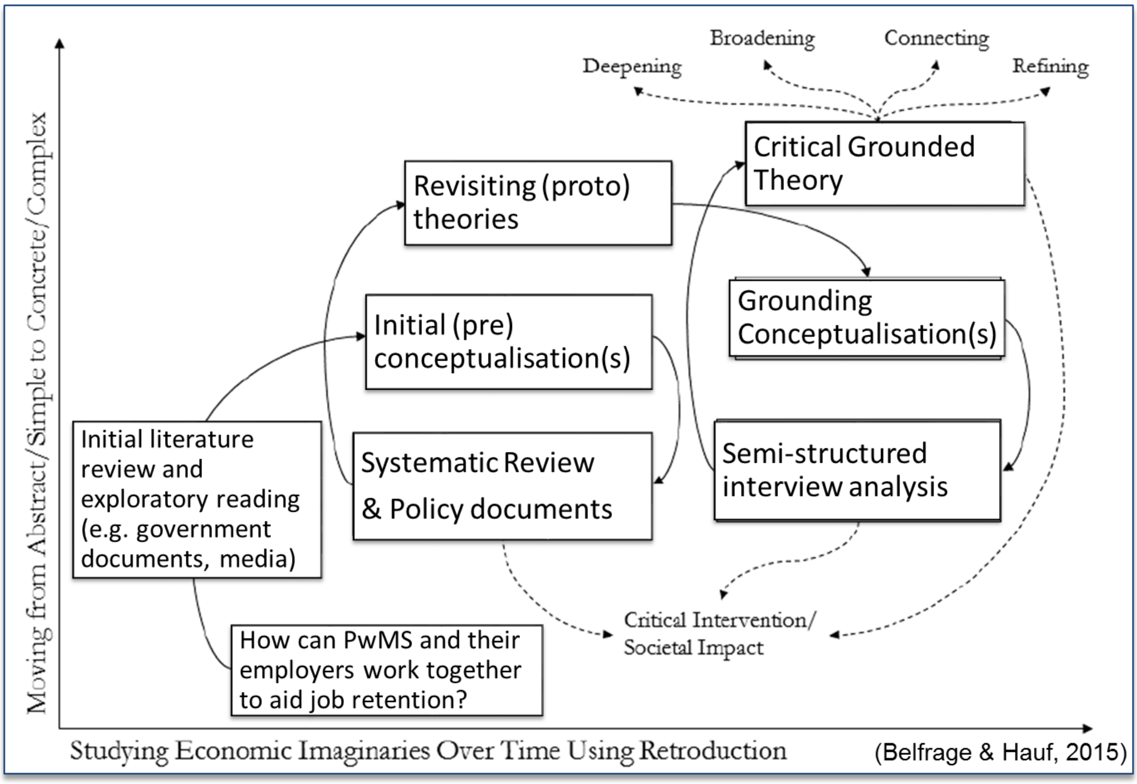

Figure 3.3 - The process applied

Method of Data Collection: Semi-structured Interviews

Qualitative data can be collected in many forms; interviews, focus groups, technical literature, to name some. Although all have benefits and limitations, the most appropriate method chosen for this study was semi-structured interviews. This incorporates an ‘interview guide’ which the researcher uses to gently guide the participant through a list of possible topics but allowing the participant to ultimately dictate which and what aspects of these topics are important to them. This keeps the interviews relevant, whilst remaining open for the participant to present their own constructs. Although classical Grounded Theory may suggest that the interviewer gives control of the dynamic of the conversation over to the interviewee, in Critical Grounded Theory, it is preferred that the researcher is open and upfront with her initial conceptualisations, so as to explore further how these fit with the constructs held by the participant (Belfrage & Hauf, 2016).

Semi-structured interviews create a platform for participants to express what experiences are meaningful to them, gently guided by the topic of interest to the researcher. McAdams (1993) said “*if you want to know me, then you must know my story, for my story defines who I am. And I want to know myself, to gain insight into the meaning of my own life, then I, too, must come to know my own story*.” (p. 11). McAdams describes the concept of personal myth – the unique stories each of us creates to narrate our lives and own experience. We are the heroic character of our own personal myth and it allows us to make sense and meaning of our experiences whilst highlighting what is true and important to us. These personal myths are carved from infancy, before sense of self even truly begins, and develop as we do in age, to define our overall identity.

Interviews allow us to see the outlines of internalised personal myths. Although there is chance one may elaborate, twist, or miss certain features of their story, McAdams argues that it is hardly possible to create an entire personal myth in the duration of an interview. However, our stories are not told simply as administrative records of events, but rather logged by meaning and impact. Rouse (1978) said that “*Truth is not simply what happened, but how we felt about it when it was happening, and how we feel about it now*.” (p.99).

This study is interested not only in the events that take place surrounding employment with MS, but how the meanings that are derived from these interactions can shape the overall context at play. In order to understand the potential ways to increase work retention for people with MS, it is key to explore these complex systems in place that can create not just physical but societal barriers.

Data will be collected through semi-structured interviews with PwMS, health professionals, and employer representatives. It is anticipated that interviews will last approximately one hour. Interview data will be supplemented by policies and procedures documents provided by employers where relevant, as well as demographic survey data from all participants. The researcher will conduct the interviews at a pre-arranged time and place that has been agreed with each participant. The interviews can be conducted face-to-face, over the telephone or through Skype calling. However, during telephone or Skype interviews, the participant must be in a private room where they will not be overheard. If conducted at the University, the researcher will arrange to conduct these from a pre-booked private room or, if visiting participants off-site, that the participant has a suitable room available.

Interviews allow participants to tell their story and to provide information about what has been important to them in relation to job retention, barriers to job retention, and – for health professionals and employers - facilitating PwMS to make choices in relation to job retention. The semi-structured interview format allows the researcher to pre-empt important topics, facilitate participants to tell their story through the use of helpful prompts, and allows for flexibility of topic and topic order.

Distrust and discomfort may arise in the interview relationship, due to perceived societal hierarchies or internal working models. Men, for example, when discussing disability, may feel defensive of their 'masculinity'. Thus, it is imperative that I, as a relatively young, Caucasian, female researcher recognise my position as an 'outsider' in these situations, lacking tangible knowledge of the experiences with which they are presented. Ann Oakley (1981), a pioneer in second wave feminist research, argued the case that interviewing is best performed when the relationship between the researcher and the interviewee is non-hierarchical. By this, she refers to social hierarchies, for example a white male has a higher standing than a white female, and a white female than a black female. Vickers (e.g. 2002) and Werth (e.g. 2015) extend this approach to advocate the benefits of what they term 'insider' research, by which the researcher is able to connect more profoundly with the participant and create a rapport based on the mutual experience of being in a marginalized group, for example, as a person with disability.

As a self-disclosed person with MS, Vickers has produced a significant amount of literature in which she derives from her own experiences to contribute to the interpretation of her data (2002, 2009a, 2009b, 2010, 2012a, 2012b, 2014a, 2014b, 2015a, 2015b, 2017). However, this approach can bring inherent risks to the quality of data, which Oakley also addresses. For example, participants that recognise these in-group characteristics may become acutely interested in the perspectives of the researcher, diverting the focus of the interview. Oakley discusses how, when interviewing women on their experiences of childbirth, many participants would ask her questions which they presumably would not to a male (who could not be considered to share the same experiences as new mothers at this time). This invariably made conducting the interview, and maintaining a neutral position, difficult. Moreover, approaching qualitative interviews from an 'insider' perspective carries the risk of misinterpreting or inadvertently overlooking opportunities to gather in-depth data due to an assumption of a shared understanding or experience. Vickers writes: "*But the really good thing about my heartbreak has been that it has helped me recognize and zero in on the heartbreak of others—*

especially those with MS—even when their heart-break is held in the chains of their too few words." (Vickers, 2015a, p. 85).

As such, there are benefits that could be argued for not being an insider. Approaching an interview in the role of 'naïve listener', I must ensure that I gather as much information as I can from the participant to ensure I do not misconstrue any of their insights. I shift the onus onto the participant to help me understand and authentically portray their experiences and interpretations.

It is of particular interest that the literature review found very few authors who disclose having MS themselves. This begs the question, as to whether the majority of researchers do not MS, or is it that they simply are not disclosing it? If the latter, this could highlight the continued stigma of MS, even within this area of research. Alternatively, it could be that there is a systematic disadvantage to PwMS, preventing them from succeeding in a career in academic research.

Supplementary data collection

Prior to qualitative interview data, participants who agree to take part in the study will be sent a link to a pre-interview questionnaire to be completed online. This pre-interview questionnaire is designed to route each participant through an appropriate pathway of questions based on the data set they belong to (see Figure 3.4). This questionnaire will collect demographic details which will help to inform the researcher, so that qualitative interviews can remain focused and relevant. The questionnaires were pre-piloted by representatives of each data set, to ensure the phrasing of questions were appropriate as well as sensitive. This pre-piloting received very positive feedback, which was discussed and utilized where feasible.

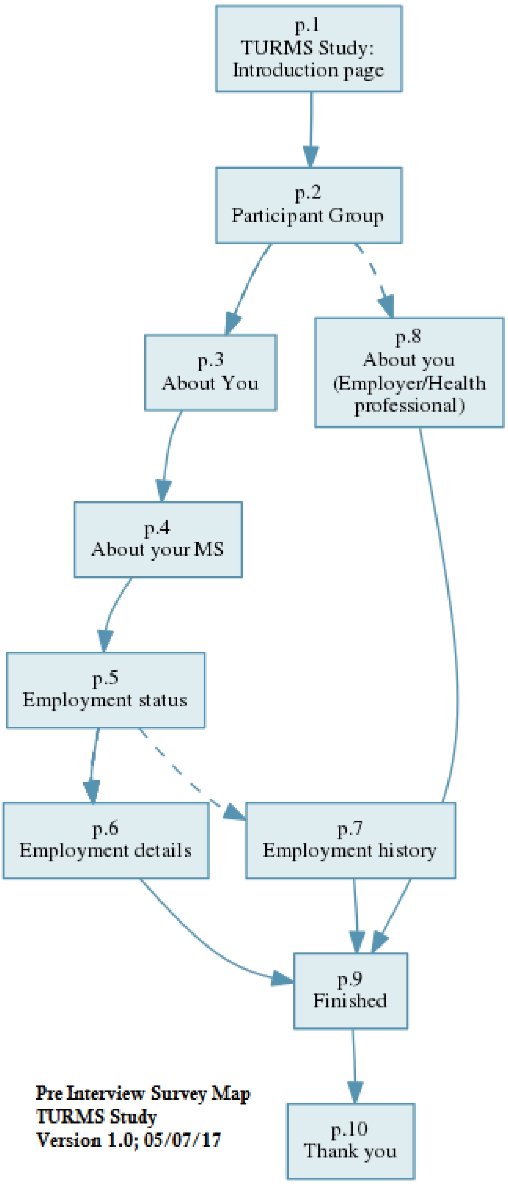

Figure 3.4 - Map of Pre-interview Survey Route

Evaluation of Interview Data

Interviews were audio recorded according to the format of the interview; for example, telephone interviews were audio recorded using a voice-recorder that could be connected to the telephone. Audio recorded files were then transcribed so that the data could be reviewed in text format. Whilst text format is not necessarily essential to coding, transcribing the data in this way has the benefit of making text easily navigated and visible. Previous authors/epidemiologists have argued that in order to truly immerse oneself in the data, transcription should be carried out by the researcher. Initially, I felt this would be beneficial for analysis in order to be involved with the data at each point, as well as reducing time required to review and complete open coding. However, there is no evidence that completing the transcription adds any additional validity to the data evaluation process.

Transcription is simply an administrative exercise, in which the words are heard individually, and without context, then reproduced as text. This does not offer the researcher a distinct opportunity to immerse herself in the meaning of the data. As such, transcription was outsourced to a company that specialises in this work, so that the researchers time could be dedicated to reviewing relevant documents for the purposes of conceptualisation, as outlined in the retroductive model above (Figures 3.2 and 3.3).

Data Set

In total, 24 participants took part in research interviews. This included 8 PwMS in paid work, 6 PwMS no longer in paid work, 8 HCPs and 2 employers. Of PwMS in paid work, three were male and five were female. This is consistent with reported MS incidence ratios in the general population of 2.4 (or 2.5:5) (Mackenzie, Morant, Bloomfield, MacDonald, & O'Riordan, 2014). This subset included 7 Caucasian and only 1 Asian participant. Ages ranged between 20 and 54 (Mean age 39.25 years). Four participants were employed in the private sector, 2 in the public sector and 1 in community/charity sector. PwMS no longer in paid work included one male and five female self-assigned participants. All participants in this subset were Caucasian. Ages ranged between 50 and 56 years (Mean age 51 years). All of the HCPs were working in public sector roles. Given the National Health Service (NHS) system in the UK, this is not unusual, although a private sector health practitioner likely would have offered distinct experiences to share. The HCP subset consisted of 3 males and 5 females. 7 participants were Caucasian, and 1 participant was Asian British. HCPs included a Consultant Neurologist, 2 MS Specialist nurses, an MS support nurse, a Neuropsychologist, a Physiotherapist, an Occupational therapist (OT) and a General practitioner (GP). Purposive sampling was used to maximise saturation of the potential range of specialists involved in the health management of people with MS. Of the 2 employers, both were female and representative of public sector work. This subset included 1 HR manager and 1 HR advisor. Detailed demographics are provided in Table 3.1.

Despite extensive recruitment efforts, employers were notably difficult to recruit to this study. Identifying relevant employers was a challenge. Although employers of PwMS participating in the study were not excluded, it was ethically preferable to allow the participant with MS to nominate their employer if they chose to do so. Understandably, PwMS may feel vulnerable or reluctant to nominate their employers. Where employers were identified independently, employers did not wish to participate in the study.

Interviews lasted between 34 minutes and 1 hour 41 minutes, with the average length of interview at 1 hour 12 minutes. Details of interview length by subset are provided in each of the relevant analysis chapters. Audio recordings of the interviews were transcribed verbatim. Transcription was conducted by an external company. The interviewer checked accuracy of the transcripts against the audio recordings during analysis.

Analysis utilized critical grounded theory methods as set out by Belfrage and Haufe (2016). First stages of coding involved reading manuscripts multiple times as well as reading manuscripts alongside listening to the audio-recordings to determine any nuances in emphasis or meaning.

Table 3.1 - Demographic details of data sets

Subset	Pseudonym	Age	Gender	Ethnicity	Type of MS	Job title	Work type	Sector	Contract type	Work classification	Organisational size
1a: PwMS in paid work	William	35	Male	Caucasian (White)	RR	Managing Director	Full-time employed	Community	Permanent	White collar	Micro
	Wendy	36	Female	Caucasian (White)	RR	Administrator	Self-employed (full-time)	Private	Consultancy	White collar	Medium
	Willow	20	Female	Caucasian (White)	RR	Sales Adviser	Part-time employed	Private	Permanent	Pink collar	Large
	Winona	38	Female	Asian/ Asian British	RR	Translator/Analyst	Full-time employed	Private	Permanent	Not sure/ Mixed	Medium
	Wayne	41	Male	Caucasian (White)	RR	Auxiliary Nurse	Part-time employed	Public	Permanent	Not sure/ Mixed	Large
	Winnifred	38	Female	Caucasian (White)	RR	Health and Wellbeing Officer	Full-time employed	Public	Permanent	White collar	Large
	Wallace	54	Male	Caucasian (White)	RR	Plumbing and Heating Engineer	Self-employed (full-time)	Private	Consultancy	Blue collar	Small
	Wilma	52	Female	Caucasian (White)	RR	Administrator	Full-time employed	Public	Permanent	White collar	Large
1b: PwMS no longer in paid work	Nicola	50	Female	Caucasian (White)	PP	Office Administrator	Not in paid employment	Private	Permanent	White collar	Small
	Naomi	55	Female	Caucasian (White)	RR	Secondary School Teacher	Not in paid employment	Public	Permanent	White collar	Medium
	Neil	54	Male	Caucasian (White)	SP	Consultant Anaesthetist	Not in paid employment	Public	Permanent	White collar	Large
	Nelly	43	Female	Caucasian (White)	RR	Career coach	Not in paid employment	Public	Permanent	White collar	Large
	Niamh	52	Female	Caucasian (White)	SP	Cleaning supervisor	Not in paid employment	Private	Permanent	Blue collar	Large
	Natalie	56	Female	Caucasian (White)	RES	Community Matron	Not in paid employment	Public	Permanent	Pink collar	Large
2: HCPs	Howard	-	Male	Asian/ Asian British	-	Consultant Neurologist	Full-time employed	Public	-	-	Large
	Harriet	-	Female	Caucasian (White)	-	MS Support Nurse	Part-time employed	Public	-	-	Large
	Hayley	-	Female	Caucasian (White)	-	Multiple Sclerosis Specialist Nurse	Full-time employed	Public	-	-	Large
	Hannah	-	Female	Caucasian (White)	-	Multiple Sclerosis Specialist Nurse	Full-time employed	Public	-	-	Large
	Henry	-	Male	Caucasian (White)	-	Neuropsychologist	Full-time employed	Public	-	-	Large
	Hugo	-	Male	Caucasian (White)	-	General Practitioner	Part-time employed	Public	-	-	Small
	Holly	-	Female	Caucasian (White)	-	MS Specialist Physiotherapist	Full-time employed	Public	-	-	Large
	Hilary	-	Female	Caucasian (White)	-	MS Specialist Occupational Therapist	Part-time employed	Public	-	-	Large
3: Employers	Esther	-	Female	Caucasian (White)	-	Senior HR Manager	Part-time employed	Public	-	-	Large
	Elizabeth	-	Female	Caucasian (White)	-	HR adviser	Full-time employed	Public	-	-	Large

PwMS – People with MS; HCPs – Healthcare professionals; RR – Relapsing-remitting; PP – Primary progressive; SP – Secondary progressive; RES – Rapidly evolving severe; Organisational size is defined as Large – More than 250 employees; Medium – 50 < 250 employees; Small – 10 < 50 employees; Micro - > 10 employees

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Chapter 4: Analysis: People with Multiple Sclerosis in Paid Employment

Introduction

People with MS (PwMS) leave work earlier than expected (Doogan & Playford, 2014; Kornblith, la Rocca, & Baum, 1986; Wetherly & McIntosh, 2016). Although studies have found that physical decline and fatigue have a role to play (O'Connor, Cano, Torrenta, Thompson, & Playford, 2005; Raggi et al., 2016), this is not the whole story. For example, Ford, Wicks, Stroud, and Tennant (2019) found that psychological factors such as self-efficacy were linked to greater work instability. Further, studies are beginning to look at psychosocial factors such as attitudes to work and job retention for PwMS (Ponzio, Brichetto, Zaratin, & Battaglia, 2015). However, the literature appears to be limited in qualitative inquiry related to psychosocial and contextual barriers.

As such, this study sought to explore the employment experiences of PwMS currently in paid work to better understand potential barriers and facilitators. The objectives were to interview 6-8 PwMS in paid employment covering a broad range of demographics for intense representation.

Data collection

Sampling was purposive. Links with the local MS clinician team and MS charities were utilised, as well as advertising through social media platforms. Further details are provided in the methodology chapter.

Semi-structured interviews were used, with opportunity for the participant to direct the conversation according to his/her priorities. The interviewer made use of an interview guide specific to this group (Appendix C.1). Broad topics covered were diagnosis experience, previous job roles, disclosure experiences, support at work and thoughts about leaving work. The interviewer probed for further detail to responses throughout the interview and clarified certain responses to avoid assumptions. The interviewer also allowed periods of no questioning so that the participant had opportunities to consider and develop their answers.

7 participants were identified, seeking a relevant range across job sector, type of work, ethnicity, and gender. 3 males and 4 females were invited for interview. 3 participants worked in a “white collar” role, 2 in a “pink collar”, 1 in a “blue collar” and 1 in a mixed role. 4 were based in a private sector role, 2 in public and 1 in community sector. There were 3 participants working in large (> 250 employees) organisations, 2 in medium (50 ≤ 250 employees) and 2 in micro-organisations (≤ 10 employees). 3 were in full time employment, 2 were in part-time and 2 were self-employed. All participants had relapsing-remitting type MS. One participant was British Asian and 6 were

Caucasian. No participants were Black British. Unfortunately, limitations in time and resources of this study meant that it was not feasible to find a representative of this marginalised group.

Interviews lasted between 1 hour 8 minutes and 1 hour 39 minutes, with the average length of interview at 1 hour 23 minutes. Transcription was conducted by an external company and checked by the researcher during analysis. Analysis utilized critical grounded theory methods as set out by Belfrage and Haufe (2016). Further details are given in the methodology chapter.

Analysis and Model

Analysis of the interviews with people with MS in paid employment identified five themes: (1) *Social role,* (2) *(Il)legitimacy processes,* (3) *(Social) value,* (4) *Togetherness,* and (5) *Adjustment process*. Each theme consists of sub- and, sometimes, sub-sub-themes.

Each (sub-)theme is relevant to at least one of three socio-economic levels: macro, meso and micro. (Sub-)themes relevant at the macro-level are governed by societal systems and norms. (Sub-)themes relevant at the meso-level involve mechanisms which occur within individual organisations. (Sub-)themes relevant at the micro-level comprises individual and interpersonal dynamics. The level at which (sub-)theme is operant is specified in the following analysis. Commensurate with the foundational interest of grounded theory in basic social processes (Glaser, 2005), two of these five themes are processual. First, the *(Il)legitimacy process* captures the way in which people with MS must continually validate, legitimise, and reaffirm their needs and experiences. Second, the *Adjustment process* describes how managing uncertainty plays a major role in the lives of people with MS in paid employment.

These five themes, and their sub-theme constituents, are integrated into a model of the experiences of people with MS in paid employment. Accounting for the macro-, meso-, and micro-levels within and across each (sub-)theme, and processes related to (ill)legitimacy and adjustment were central to the development of the model below (Figure 4.1).

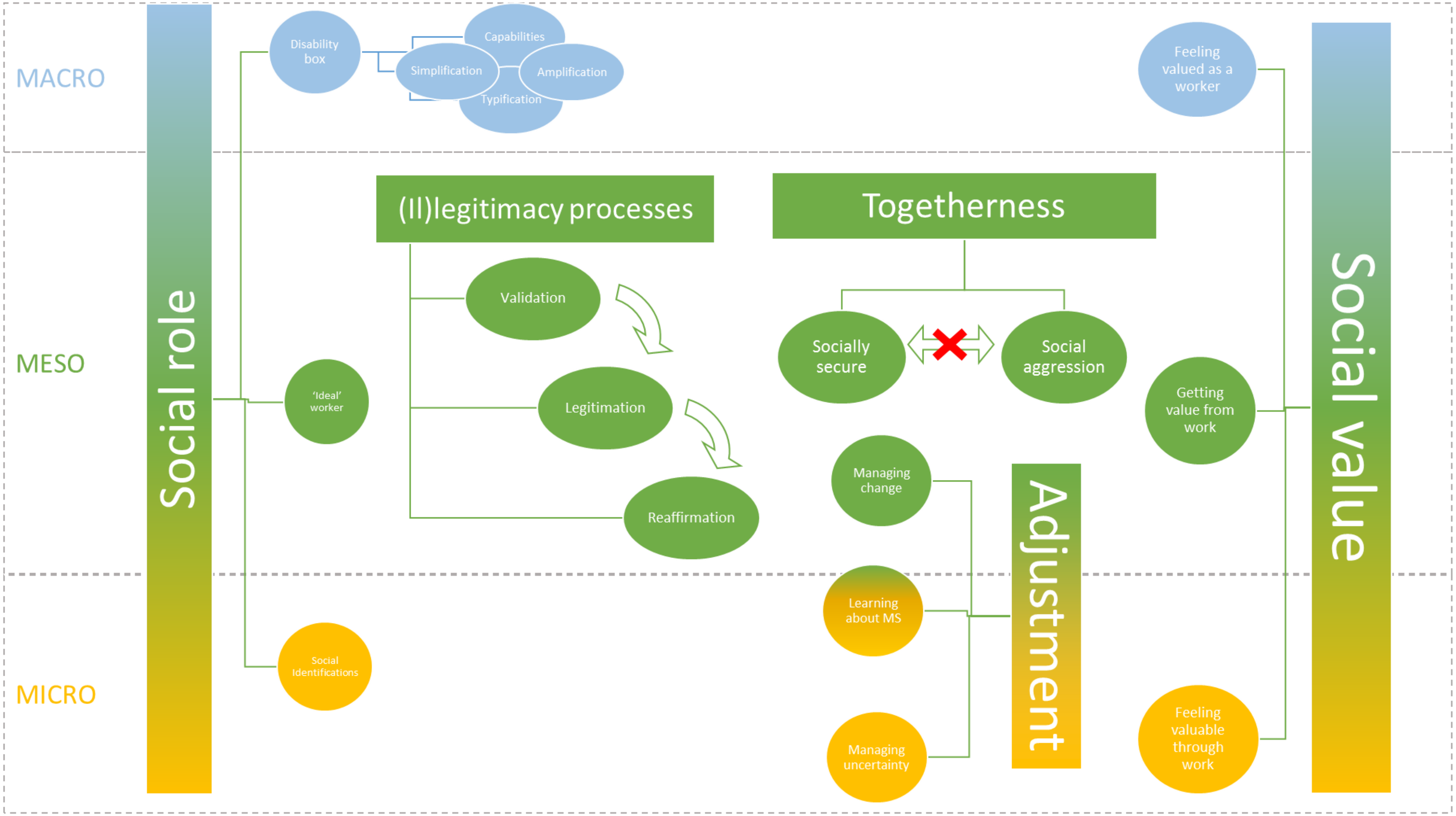

Figure 4.1 - Model of the experience of people with MS in paid employment

Theme 1: Social Role (micro, meso and macro levels)

Participants with MS define themselves according to certain social roles, and this contributes to their interactions with the people and environment around them. However, a diagnosis of MS can be problematic in maintaining a previously self-assigned social role.

Functioning within a perceived social role can foster a sense of security to an individual; for some, the thought of parting with that role can be terrifying. From the time of diagnosis of MS, an individual's role and identity can begin to feel threatened. In the first instance, the decision to disclose means putting out a new identity of "disabled" or "chronically ill", which the individual may not personally identify with. Some participants were wary of disclosing their MS due to the changes this could trigger to their social identity.

Theme 1: Social Role; Sub-theme 1: Social Identifications (micro: personal level)

Social identifications refer to the social roles defined at an individual level: self-identifications, our internal narrative, and the character we play in our life stories. Social identifications play a part in how PwMS interact with their MS and their work. A few participants identified the role of Class as a contributing factor of peoples' attitudes to work. Those who self-identified as working-class considered that their middle-class counterparts were privileged and did not necessarily understand true hardship. Meanwhile, those that described themselves as middle class described a stereotype of the working class being "lazy" or lacking work ethic. However, it seems more likely that these social identifications are used by individuals to help articulate the traits they like to see in themselves:

> *"…but I've still got that working class sort of, what I think is like a working class ethic that you just get on with things…" Winifred*

Winifred considers herself working class and feels a strong sense of self from the traits she deems this categorisation has afforded her. This provides a foundation to her internal narrative that she can structure her identity around. She is able to use this group mentality to strengthen her social bonding:

> *"… we're more like your down to earth sort of real people, like we understand real world, and then we've got another set of colleagues that live in like a little bubble, and think they understand stuff but they don't, they've been brought up very differently to how we are…" Winifred*

In describing her working-class colleagues as her "real people", Winifred expresses the very real impact the social construction of class systems has in her interpersonal experiences.

Although class is a tool here to distinguish these groups, it is perhaps more important that this social concept has facilitated positive interpersonal relations, enabling Winifred to feel understood and supported in a way that agrees with aspects of her own sense of self. This group mentality is not so much about disliking other groups, but a way to reinforce the validity of our experiences with kindred minds.

These strong interpersonal relationships have provided a secure social environment for Winifred in the workplace, which has been beneficial to her continuing work. Interestingly, Willow also discussed social class, but had a different conclusion. While Winifred sees that it is the working class who work hard and "get on with things", Willow confesses that her assumptions of working class were grouped with less desirable traits:

> *"…I have been guilty of thinking, oh people on Jobseekers are just lazy people that don't get off the couch, live in council houses and, you know, working class people…" Willow*

However, Willow considers that what Winifred describes as a 'working class ethic' is not so much a class trait as a 'British' characteristic:

> *"It's kind of like the British tradition isn't it, stiff upper lip, grin and bear it." Willow*

To what extent there is a tendency for certain groups, whether it is due to class or nationality, to display particular traits is not clear here. However, making use of these social identifications to feel connected to those around us is key to feeling secure in our own sense of self. For Wallace, his coping mechanisms were based in being self-sustaining. Therefore, being self-employed was a key aspect of his narrative for how he was able to manage the challenges of working with MS.

> *"Because, if you're employed, you've got somebody you can blame or pursue or, you know, I don't know, there's a lot of that goes on, I'm sure, but there isn't if you're self-employed, it's you, you take responsibility for your situation." Wallace*

Thus, self-assigning these social roles can be useful in understanding self-identities as well as serving as a coping strategy during challenges.

Theme 1: Social Role; Sub-theme 2: 'Ideal' worker (meso: organisational level)

Ingrained in some organisational cultures is that to be a good worker means being seen as constantly busy, and never being ill. Of course, this is unreasonable, even for an able-bodied person, to attain, let alone someone with a chronic illness. This theme of the ideal worker may present differently depending on the organisational culture, making it easier or more difficult for an individual with MS to meet these expectations.

This *'Ideal' worker* sub-theme encompasses the expectation of how an employee completes their work, regardless of the result. While this may vary by organisation, barriers to work arise where employers' expectations are founded in able-bodied norms. Despite a reasonable potential for adjustments, for some employers, worker norms become the 'unbreakable rule':

> *"And I said to them, "In my previous job role I actually found it really helpful to have the capacity to work from home because with MS sometimes I*

> *can't feel my feet, so there are a number of reasons why I might be unsteady and not feel able to get up, get dressed, walk to the bus stop, get a bus to work and come and do my job, but if I can get up in my pyjamas and log on, I can continue to do good work, you don't have a day of staff absence, and I don't have an absence and therefore a problem with my pay that month, so it's… so really I kind of see it as a win-win," and they were like, "Well we don't do working from home," and I'm like, "Yes, I see that." [Both laugh]" Wendy*

For Wendy, when working in a private firm, the 'ideal' worker was expected to be visibly dedicated to long stints of work with few breaks. Thus, taking regular breaks or seeking accommodations such as working from home (somewhere she could not be visibly seen working) led to the perception that she may be 'shirking', or trying to get special treatment. Ironically, Wendy's requests for adjustments in the workplace are simply an attempt to try to reach equivalency. Contrarily, Winona found her employers very flexible around working styles, and this enabled her to work more effectively.

> *"I mean, flexible working hours actually came in because with my job, it's very easy to see, um, how productive in what you do […] every analyst has their productivity, um, monitored, basically by the number of translations they are doing per day […] and my productivity though had, had basically had plummeted, because my fatigue was so bad, and that came up as a red light […] I suggested, you know, could flexible working hours be a possibility, erm and yeah, and they were, you know, they were open to it" Winona*

Interestingly, Winona notes that flexible working was possible due to the ease of monitoring work productivity. She also comments that she feels lucky that her employers have granted homeworking to her, as she states "*…trying to find any kind of job where home-working is a standard, […] they're few and far between.*"

While a minimum level of productivity may be the expectation at work, some participants felt that these expectations extended to working beyond the agreed parameters of their role:

> *"…so I could cut to three days, but then potentially I'd end up just doing as much anyway, so like if I didn't get a piece of work finished I am, you know, like, so like with my Fridays that I have off, I am flexible with that, so if I do need to do more or switch my days around I then do say, "Oh I'll come in on that Friday," and so I think there'd always be that fear that even though in reality I'd cut to three days that I was still doing maybe the four days that I do now, just not getting paid for it." Winifred*

Here, we see that Winifred feels she would find herself having to prioritise work even if she were to reduce her contracted hours. Rather than reducing the actual work output required, she feels the reduction would be only to her wages.

These high expectations placed on employees can roll over into attendance management. Despite a legal entitlement to sick leave in the UK, some employers may expect to have workers who do not expend such absences. The implication here is that getting sick is as a form of laziness, as though people are able to bypass their immune functioning just by being more disciplined in their work ethic.

> *"That's the other thing she said to me, yeah, 'I want to employ somebody with an impeccable sickness record.'" Wayne*

These kinds of expectations within UK work culture may not be limited to PwMS but can disproportionately disadvantage employees with chronic health conditions.

In addition to ideal worker expectations held by employers, PwMS may hold themselves to concepts of 'ideal' worker standards, possibly stemming from wider cultural norms. Wayne feels ashamed that he has had to reduce his hours to help manage his MS symptoms, and feels that he should be doing more hours

> *"I should be doing 37 [hours], I'm only 41, you know, I think it's a pride thing maybe, I don't know, but I do struggle with the fact that I've had to cut my hours and that, yeah." Wayne*

This ties in with feeling valuable through work, a category discussed further on in this analysis. This shame that comes with not working several hours may also be tied in with the construct that not being in paid work is equivalent to not having a work ethic, and thus being lazy. In the UK, full-time work is commonly 37.5 hours. Thus, this has become a normalised expectation of working. However, average hours worked can vary across different parts of the world, which may be reflected in societal attitudes around the concept of the 'ideal worker'.

Discussion Point: The Glass Door of Disability

Coined in the early nineties, the 'glass ceiling' is a metaphor for the barriers faced by women and minorities in the workplace. Interestingly, one participant mentioned an adapted version of this metaphor for disabled persons, the 'glass door', presumably in reference to the challenge of opening a non-power-assisted door for someone with physical disabilities. These barriers can be two-fold; firstly, the assumptions about people with chronic conditions not being as capable or being "difficult" in requiring adjustments can lead those higher in the organisation to pass them up for promotion opportunities. Secondly, that the PwMS have been unable to access suitable management strategies or are expected to complete a job role working within a structured style created for and by able-bodied people.

> *"…I heard the phrase the glass door of disability, which perhaps is slightly different but it's still the same and once you tell someone you've got MS that can lead to, yeah, a glass ceiling, a glass door, whatever the phrase is, to being promoted." William*

Regardless of the precise terminology, William is not the only participant to have noted this phenomenon. Wendy also tells me how her career advancement has been kerbed:

> *"…I felt awful, yeah, I was missing so much work, but even if it didn't lead to being directly fired, I wasn't able to access the same opportunities because*

> *there was a perception that I was a bit of a shirker, because as well because I still walk around and I still drove a car and I still, you know, have an interest in life, you know, I wear make-up, I get piercings, you know, I'm still interested in stuff, because I'm not just like biddable sick girl, her with the disability." Wendy*

She equates this to not conforming to the label of disability by societal criteria, in that she does not withdraw from the same activities as able-bodied persons.

By participating in activities outside of her work life, the assumption is that Wendy must either be functioning on par with her able-bodied counterparts or is expending her resources toward activities outside of work and therefore is not prioritising work as much as is socially expected. There is perhaps a fundamental belief that work should be prioritised at a cost to these other activities, and that an individual's accommodation needs cannot be exclusive to work activities. There is also an implication of choice on behalf of the person with MS. They are making a choice between non-work activities and work activities. Wilma experiences a similar social backlash to engaging in personal interests (music concerts) outside of work. She goes on to explain that her MS diagnosis has made it more important that she continues to pursue these interests while she "still can". On the other hand, she does not feel motivated to progress her career at the risk of exacerbating her MS:

> *"…it's not that I didn't want to get promoted in the past, but, you know it's come to the stage where I couldn't cope with it now…" Wilma*

While barriers to progression can be due to false assumptions by others, they can also be a result of the individual not feeling capable of the additional workload a promotion could entail. Progressing in some workplaces means longer hours, aside from increased skill level.

> *"…if I didn't have the MS I'd probably have wanted to progress more within the NHS, but I just think that, a) it's not a good idea anyway, I feel like I'm able to do a certain amount of hours, and b) that even if I did how long would I have been in that role before I have to give it up because it was too much anyway…" Wayne*

While this 'glass door' refers primarily to progression in the workplace, participants also commented on barriers to sideways movements, which can leave people with MS feeling insecure about changing jobs. For example, although Wayne feels secure and accepted in his current role, he is aware that this may not be the case if he were to look for another job, even within the same organisation. He feels limited to his employment choices due to his MS, which could place increased pressure to stay in a job even if it were not ideal.

For Wallace, while being self-employed gives him a greater sense of choice in the work he does, there are still limitations that he is aware of, and expectations which he must be able to meet, in order to maintain client trust:

> *"What I don't want to do is start a project and then find, for whatever reason, I can't complete it, because that's professional suicide, you know, a client is not going to forgive you, no matter what your situation is, it's, that really isn't*

> *good, and I wouldn't want somebody to do it to me. So I don't enter into, I don't start projects with clients unless I know I've got a good chance, you know, barring the unforeseen, of getting it done…" Wallace*

Disclosing a chronic condition such as MS or seeking reasonable accommodations can mean putting out an identity of 'disabled' which shoulders its own expected social role. This is explored further in the next sub-theme *'Disability box'*.

Theme 1: Social Role; Sub-theme 3: Disability Box (macro: cultural level)

Stemming from the idiom to "Get back in (one's) box" which implies a person should return to a position that attracts less attention, this theme encompasses the social construct that to be disabled or chronically ill means to withdraw from life, become dependent, and stop functioning actively in society. The notion of putting someone in a box also refers to trying to force a person to conform to a particular standard; in this sense, the expected, low profile, position of 'disabled'. Societal assumptions around disability appear to expect someone weak, immobile, or incapable. However, many employees with MS will not identify with this description. Moreover, some people with MS may not identify with being disabled at all.

In addition to assumptions of disability and ideal work, people's relative knowledge of MS and what it means can be discordant with individual-level experiences of MS. The individual with MS can feel that their condition becomes central to others' perception of them as members of society and as employees.

Theme 1: Social Role; Sub-theme 3: Disability Box; Sub-sub-theme 1: Typification

Creating social constructions based on a set of standard assumptions is called *Typification* (Oesterdiekhoff, 2009). MS is a highly individualistic condition and can affect everybody with this diagnosis differently. Telling someone you have MS does not really tell them much. This is summarised well by Willow:

> *"I think you'd have to have like a separate essay worth of pages, just explaining your MS, because like I said, every patient's different, so you know like, if you just put on your CV, you know, notes, I have MS, an employer straightaway will be like, well no, you can't do our job, because you know, they assume that you can't walk, you can't do this, you can't do that." Willow*

Employers and co-workers may make assumptions about a person based on their limited experience or knowledge of MS. However, the label 'MS' is not particularly helpful when assessing an individual's needs or capabilities. For Wilma, despite being open about her MS diagnosis, she feels that people conflate chronic illness with an external healthy appearance.

> *"I try and explain a bit about the condition, try and explain to people how it affects you. But I still think there's a lot of disbelief that I'm actually ill because I actually look really healthy [...] people think, oh well, you know, she looks*

> *perfectly healthy, you know, she's only a size 10, blah-de-blah-de-blah, and it's like, but I work at it, and I try and keep myself healthy…" Wilma*

This is especially frustrating for Wilma, who discusses that she tries to maintain a healthy lifestyle through diet and exercise as a way to try and minimise the impact of her MS; ironically, this has pushed her further away from socially expected norms of what disability ought to look like. Interestingly, at some point in each of the interviews, the perception of MS being a wheelchair-user was raised, usually in relation to the time of diagnosis or prior to having much knowledge of MS. However, MS can progress and present in variable ways, which PwMS may find themselves having to explain to employers.

> *"…I did have to actively, and very consciously make clear was that everybody with MS is different […] Just because I'm able to manage this, this and this doesn't automatically mean she is able to do it because of the state of her MS." Winona*

Theme 1: Social Role; Sub-theme 3: Disability Box; Sub-sub-theme 2: Simplification

Humans are complex beings, and MS is only one factor of an individual. The concept of "I am more than my MS" came up regularly. MS being just one component of an individual, it can be frustrating when others fixate on it. People do not want MS to be the only aspect of their identity considered.

Wendy discusses how those who had personal experiences with someone with a disability or impairment were able to recognise that these factors did not define an individual in some black and white way. On the other hand, she felt that some colleagues considered that her MS was the defining feature of her identity. This meant that other character traits were ignored, despite these being more meaningful to her. This creates a discord in how she is perceived by others compared with feeling acknowledged for the qualities that are important to her. She uses a slightly sardonic analogy that while she does have "*weird health problems*" she also makes great cakes and felt this should have been at least as obvious to her work colleagues:

> *"I'm fairly sure that if I was to go back to my old place of work and say, oh, you know, tell me one thing you remember about [Wendy], it'll probably be that she had the weird health problems [laughs]. I mean that sucks, because, you know, I actually make really great cakes, and indeed took them into work on several occasions" Wendy*

This centralisation of her MS above all other features presented issues when trying to discuss any concerns in the workplace. As Wendy describes, her MS label detracted from unconnected concerns that she raised with her employers:

> *[My previous employer] was so absorbed by the fact that I had something wrong with me, everything that was any kind of problem or negative event was immediately tied into the fact that I've got MS. And I was like, "No no, I'm actually just a pretty outspoken person, I'm telling you that this this and this is a*

> *problem, me having MS is kind of by-the-by and I'm still a good employee and I have an agile curious mind and I've spotted some things and I want to talk to you about that and stop mentioning the fact that I've got MS."" Wendy*

For Winifred, she describes how colleagues have been able to disentangle her MS from her overall identity, and how this has been beneficial in supporting her at work:

> *"...I quite like it that they just take, well my real people colleagues just take me as I am, and don't make it about that all the time, and so I think they can offer the right support, that they would with anybody..." Winifred*

Wayne also describes how MS does not play a major role in his identity with others; the invisibility of the condition for him means that it is his decision whether to disclose his MS. There is a certain empowerment this gives, which is apparent in the following extract:

> *"So, I mean a lot of them know about it anyway, but then sometimes I'll, sort of, talk to certain ones and they're like, 'Oh, I didn't realise you had MS,' and I'm like, 'Oh, yeah, yeah,' again, it's not because I go around with a badge or go around going, 'I've got MS,' or whatever, but they might ask me a question, because that has to be part of the answer then that's why I'll tell them. But if it's not something that relates to that question then it won't come out and so they'll never know..." Wayne*

The concept that identity should not be simplified to "having MS" is summarised well by Winifred, simply as "*I don't want MS to be me, I just want to be me*". Everyone has individual differences, and to reduce a person down to one aspect of themselves minimises all the other facets of their identity.

Theme 1: Social Role; Sub-theme 3: Disability Box; Sub-sub-theme 3: Capabilities

Further to simplifying an individual's identity to a diagnosis of MS, employees also seemed to face barriers from employers bringing to question the individual's capabilities due to their MS. This was tied into assumptions around disability, and conflating disability with MS.

> *"Yeah, they assume that you're disabled. Whereas like, you know like, actually putting in a little bit of detail what you have and your symptoms, and then maybe putting as well like, you know, this does not mean, this doesn't mean I cannot do this, it will just mean I'm limited." Willow*

Humans are all on an ability matrix and whilst having MS may present limitations in one area, it does not remove all capabilities. Some participants felt that employers had trouble divorcing an MS diagnosis from an individual's competence as an employee. This can be particularly challenging when capabilities may fluctuate alongside the condition. For others, having employers or colleagues who were able to understand that MS did not mean that they were entirely incapacitated was helpful. In the following extract, Wendy explains the strategies by which she tries to "normalise" her MS for potential employers, to help them understand that her condition is not an immediate indicator of her capacities for the role at hand:

> *"…in the interests of full transparency, I also have a neurological condition, but as you can see I've got myself here and obviously you're impressed by my CV so this does not impact on my capacities, and then as the years went on I did say things like, "I have consciously chosen roles that are predominantly office based, or where I can be comfortably seated, and I wouldn't look to do field work," basically, but just to kind of normalise for a wholly able bodied person who has no understanding of MS, because why should they, because there's so many things in the world that can go wrong with the body, you know…" Wendy*

Wallace adds to this that MS does not necessarily take away the previous skills an individual may have developed, but rather that limitations due to symptoms of MS may require a person to re-think how they can apply these skills.

> *"You don't forget everything you've learnt overnight just because something physically has happened to you, it's all there, it's just how you apply it, you know, it's a lifetime of knowledge that, it needs to be used, you don't get to know what you do overnight, it's taken me a long time" Wallace*

Theme 1: Social Role; Sub-theme 3: Disability Box; Sub-sub-theme 4: Amplification

In addition to feeling that their identities may be reduced to a label of MS, and capabilities called into question due to their MS, PwMS discussed that employers may amplify their MS and assign unwarranted significance to it. This amplification may stem from either stigmatising or paternalistic attitudes.

Wayne avoided this unwarranted attention by not disclosing his MS. On the other hand, Wendy does not hide her MS but by doing so felt exhausted by the process of having to be the educator for her employers. She describes feeling as though her employers expect her to be a "*poster girl for hidden disabilities*". In contrast, Wendy describes an experience with a manager who was able to provide an appropriately measured response to her different needs.

> *"…he didn't make it like super special, ooh, I'm doing this thing for you, he just sent me an email saying, "Oh I've seen that, you know, managers have been told that there's going to be lift maintenance on Tuesday, just mark yourself as working from home," cool, like yeah, cool, also kind of reasonable, you know […]I don't ever want to get more than or super special time, I just want to try and achieve some sort of equivalency." Wendy*

Wendy does not want special treatment, but simply wants to be on equal footing with her colleagues. Indeed, many participants noted feeling wary of not wanting undue attention or 'special treatment' due to their MS.

> *"…I don't want to be treated more specially, like I don't get more attention just because I have an illness…" Willow*

Willow does not want to be singularised by her MS and goes on to explain that it is important to be treated equally. This feeling of not wanting special treatment is also reflected by Winifred, who feels that her MS has resulted in her manager not trusting her. Winifred's manager appears to express a simultaneous perception that she is not behaving in an appropriately disabled manner, and that her MS does not warrant additional support. As she states "*...I think he's just a bit like, oh, yeah, well none of us feel well*". However, Winifred feels that she is her MS symptoms are conflated with her engaging in a meaningful life beyond work.

> *"...I feel like it's expected that I'm not allowed to do anything outside work in case that becomes the cause of why I'm not in work, it's almost like you're not allowed to do normal things, and if you do normal things, or you do things that people don't expect you should be able to do, then it's your own fault if you end up not well." Winifred*

This perception was mirrored by Wendy and Wilma, who also felt vilified for their activities outside of work. PwMS may feel that they are expected to behave within a limited role of 'disabled' both in and out of work and may experience a stigmatised response if they do not conform to these 'disabled' norms.

This also demonstrates the (il)legitimacy processes people with MS can experience in the workplace which is explored next.

Theme 2: (Il)legitimacy Processes (meso: organisational level)

In terms of MS being acknowledged and accepted in the workplace, PwMS were up against a 3-part process of potential barriers. The first, validating their MS as a real condition with real impact. Second, legitimising their adjustment needs to others; there were negative experiences in which the individual was not granted dignity and expected to divulge personal or embarrassing details in order to "justify" their adjustments. There were also positive experiences in which the individual was not "singled out" and it was generally acknowledged that they have different needs. Finally, due to the invisibility of MS, participants found themselves having to reaffirm their condition and the limitations this may bring, which could be frustrating or disheartening.

Theme 2: (Il)legitimacy Processes; Sub-theme 1: Validation (meso: organisational level)

Despite participants often explaining their MS to colleagues, there appears to be a lack of awareness or belief in the real impact MS can have. Validation of MS seems to be linked to the invisibility of symptoms; non-MSers appear to struggle to acknowledge the condition due to lack of visual cues. Some describe that MS can be seen as an excuse, or not a real condition.

A common symptom of MS that non-MSers have difficulty comprehending is fatigue. Unlike feeling tired, fatigue is debilitating and can lead to the sufferer being bed-ridden in some cases.

> *"…some people might think, oh you're just being lazy, because it's early, you'll be fine, but they don't understand that you really physically can't get out of bed…" Willow*

For one participant, despite being given a diagnosis by a health professional, colleagues were inclined to suggest that maybe her symptoms were not MS at all. Although perhaps well-intentioned and trying to offer an alternative to it being a lifelong condition, these colleagues questioned the reality of the MS:

> *I did have initially, when [laughs] two of my colleagues when I was first diagnosed, thought they were being helpful, I drink a lot of Diet Coke, and they'd brought me in these articles, that two separate people brought me in these articles and said, "I've read this about Diet Coke and how it can affect your body and I'm wondering if it's more summit like this, maybe you should think about this," [both laugh], and I was just a bit like, "Yes, if there wasn't an MRI scan and a neurologist that said it were MS maybe I would have thought that it could have been all this Diet Coke that I drink." Winifred*

Winifred makes light of the situation with sarcastic whit, "*yes, if there was not an MRI and a neurologist that said it…*" however, this is also a method of validating the authority of her diagnosis. An authoritative figure (i.e., a health professional) has confirmed it alongside an item of advanced technology (an MRI, which can produce visual evidence). The use of these to give credibility to her diagnosis suggests that Winifred lacks social power to be believed of her own accord. More seriously, Winifred notes that despite providing information booklets for her line manager, she feels that this information may be manipulated to further invalidate her, predicting that her manager's response might be "*…it says here that it can affect you all different, you know, everybody different, so you're not necessarily affected by these things here*".

PwMS are not only in a position of lower power than their employer due to the reliance on income, but also socially, their voices are less heard: their judgements are discounted, and they are not considered as knowledgeable even about their own experiences. This can be seen in the following example by Wendy:

> *"…what I did find was that some people irrespective of me sitting in front of them right here, clear as day, telling them a set of facts, would actually be hearing something completely different, and making their own set of judgements and assessments, even though I was telling them as it was, they were like, oh disabled, neurological condition, oh my gosh!" Wendy*

While Winona has had positive, validating experiences in relation to her employer and MS, she notes that legislation provides an additional sense of security and further validation to her needs.

> *"after I found out that MS was covered under the equality act, I become a lot more confident [...] I felt like, ok, I had the law on my side. And I've never had to use the equality act, and say that actually, this is what you need to be doing and*

> *it's law, because he's been very good, but knowing that I can fall back on that if necessary has given me more confidence" Winona*

Validation struggles are not limited to the symptomatic impact of MS, but the extra effort faced on a regular basis by PwMS to achieve equality. The following discussion point on the welfare system in the UK highlights some of these wider challenges faced by PwMS, which can have a contributing effect on barriers to staying in paid work.

Discussion Point: Employment Support Systems in the UK

Employment support systems across the UK can vary by employer. These systems include welfare systems related to employment support and occupational health services.

In recent years, the UK has seen dramatic changes to the welfare system, making it sometimes a challenge to navigate. However, applying for and being granted welfare is a form of validation of the impact of MS. Participants had had mixed experiences with this. Personal Independence Payments (PIP) are designed to provide financial support to individuals who may lack capacity to work full time hours. Participants that underwent assessment for PIP describe a difficult process which can be layered in uncertainty. Further, the assessment process could feel undignified and inappropriate.

> *"You then have to have a meeting, as well, which is fine, but it's just ridiculous. How far can you walk and can you do this and can you do that and, you know, it's like when you're with a doctor, can you push up, push down, pull, pulling, all that sort of thing. So, you're sort of there for about 40 minutes and then it might take them like two weeks to decide what they're going to do. So, like, I did get it originally, years ago, and then I got assessed again and then they took it from me." Wayne*

The PIP system is not designed well for fluctuating conditions such as MS and is more suited to a trajectory of debility followed by recovery. In addition to being a challenging process, there appears to be inconsistencies with being considered "ill enough". In Willow's case, referral to PIP assessments came across as a challenge against her diagnosis, ultimately leading to disappointment.

> *"[Willow]: So, you know, when you think a Job Centre refers you, you sort of get your hopes up, because you think, oh they can clearly see that maybe I deserve this, and then they turn you down.*
>
> *[Willow]'s mum: It was probably as well, because they probably [pause] maybe they didn't believe that you've got MS, so they wanted you to go for the assessment."*

Willow's mum, who was present for her interview, considered that the assessment was a tool used by the Jobseeker Centre to test the validity of her condition. Wilma experienced challenges to the validity of her employment related adjustment needs during an occupational health meeting.

> *"…and then [Occupational health] said "well how can you do all this walking if you struggle to get up?" I said, "I didn't say there was any physical*

> *reason why I can't get up, it's cognitive." I've lay in bed, and I will just lay there and I think, "right, I should get up, right I should get up" but it'll take me probably about an hour to get up which is why I'm allowed to go in work later. And she wasn't, she just seemed very rude and very dismissive." Wilma*

Wilma continues that the occupational health representative then challenged the validity of her reasonable adjustments, increasing her uncertainty and insecurity in relation to her work.

Theme 2: (Il)legitimacy Processes; Sub-theme 2: Legitimation (meso: organisational level)

One participant with MS discussed the imbalance of needing to disclose or even legitimise their condition with sharing additional personal details of the impact of MS. This results in the person with MS feeling vulnerable in the social exchange by sharing personal details with no reciprocation.

> "*…when you are over sharing to almost legitimise your working needs, experiences, then it feels very imbalanced because that person that you're talking to very rarely then shares something of themselves, they just take that from you and go, huh, alright, well I can kind of see, I can kind of see your point, alright then, and they go about their business. And I'm like, oh so I've told you all this stuff now and now I feel very exposed and very vulnerable, but you now maybe don't think I'm such a shirker because I've told you whatever kind of details were appropriate at the time, but then they just waltz off and go about their business. So it's like psychologically it's difficult…" Wendy*

PwMS may face hesitancy with how much information to share regarding the ways in which MS is impacting them. For Wendy, legitimising her needs as someone with MS meant opening herself up to vulnerability and possibly humiliation, but it was preferable to being falsely accused of being lazy in her work ethic. Had there already existed an interpersonal relationship of trust and respect between her and her employer, this may have been an opportunity to present a positive experience in which she felt validated and secure. However, in this case, it created an additional barrier to a positive working relationship.

Wayne had a quite different experience in terms of legitimisation of his MS. Wayne describes his experience of feeling validated through not having to further legitimise his needs and the positive impact of this.

> *"I could say to them, 'Can you refer that to occupational health tomorrow?' And they'd get me an appointment or whatever and then I could go to him and say, 'Right, I want you to dictate a letter to the sisters saying that as of next week I'm no longer allowed to go down to medical records and collect the trolleys, because it's far too physically tiring for me.' And he would do that and they would implement that, you know?" Wayne*

For William, legitimation is so central to his organisation's values that considering whether adjustments had even been made was a challenge for him during the interview.

> *"Um, do I have adjustments set in place? I'm sure I do as well but it's because they're so second nature and just part of it, it's almost quite hard to unpick what they are." William*

In this respect, legitimising his MS was not even a consideration for William. Providing a secure work environment for PwMS is clearly linked to validation, and an environment in which employees do not feel the legitimacy of their MS or MS-related needs are challenged.

Theme 2: (Il)legitimacy Processes; Sub-theme 3: Reaffirmation (meso: organisational level)

Not only were MSers having to convince those around them that their condition and symptoms were very much real (validation) and having to explain *why* they were working 'differently' (legitimation), but often had to reaffirm their different needs due to co-workers or employers forgetting about their MS.

Willow found that during her time with Jobseekers, she was repeatedly having to reaffirm her MS and the limits this set on her working hours:

> *"Yeah, they kept saying, oh we've found this job, and it was like, oh it's a full-time job doing this and that, and it's like, well I can't you know, I physically will not do that, my body will just not accept that." Willow*

On the other hand, employers with a good grasp of MS and its fluctuating nature were able to recognise that their workplace policies may require exceptions. For Wayne, the policies related to absence may have seen him face disciplinary action had his line managers been less understanding of his MS (and their obligations related to disability discrimination):

> *"The [employers] were like, 'No, you can't penalise [Wayne] for having MS. It's a condition that he isn't able to control, and at least he's still coming to work and that's what we need to support him, and we need to support him in the role, at least he's trying and he's coming to work and he's doing his job.'" Wayne*

By recognising that MS can involve episodes of relapse, Wayne's employers were able to make him feel validated and affirmed, supporting him to continue working.

Winifred feels conflicted in wanting others to recognise her MS, in that she wants to be treated as an equal to her counterparts, but also to be given fair treatment for her different needs:

> "*…sometimes I think people do forget what you've to do, so sometimes she throws pieces of work at me, but then I don't think it's any different to anybody else, so it's almost like I want it both ways I suppose, I don't want to be treated any differently, but then sometimes I want to be given a bit of a break, yeah, and for people to realise that it's not useful to sort of pile things up." Winifred*

This encapsulates the balance people with MS are often struggling to find, in not wanting to be alienated while wanting to be given equal opportunities based on their current capabilities.

Theme 3: Social value (micro, meso and macro levels)

Part of living and working within a capitalist society might mean being expected to conform to the perception that paid employment equates to social value. But social value can go beyond economic value or human capital. Individuals may feel valuable socially through the activities of paid work, as well as extracting value from doing work. Further, individuals may feel valued by their employer in the workplace for the work they do.

Theme 3: Social Value; Sub-theme 1: Feeling Valuable through Work (micro: personal level)

Consistent with the theme of the *'Ideal' worker*, maintaining paid employment helps individuals to feel valuable in society. Feeling valuable is important to a person's self-worth and confidence. William explains the detrimental impact of not feeling valuable through work.

> *"…I wasn't giving 100% and the value that I was bringing to the team which wasn't of a high enough standard, so it was like "what do we, how can G, what can he do?" And that was, yeah, the impact on my confidence and my feeling of self-worth was significant." William*

William's employer offered full salary during the period following his diagnosis, when he felt he "*offered very little benefit*", furthering the gap between the value he felt he offered his employer and what his employer afforded him. Engagement in work can make individuals feel valuable to society.

> *"…as long as I'm in work and have a job and come home and know that I'm contributing, then I'm happy, you know?" Wayne*

Wallace felt that work was linked to a sense of pride that he was able to maintain through continuing to work through self-employment.

> *"I've wanted to carry on working because I enjoy it, I don't enjoy all of it, but I enjoy a lot of aspects of it because you take a, and certainly self-employment brings a certain pride in what you do…" Wallace*

Work can also serve as a gauge for functioning, wellbeing, and health. Participants reflected on fears that leaving work would likely be an indication that their health had deteriorated significantly, also suggesting they might not be able to contribute value to society after work.

Theme 3: Social Value; Sub-theme 2: Getting Value from Work (meso: organisational level)

In addition to feeling valuable through paid work, participants discuss how work gives them purpose and benefits beyond an income.

> *"…it's still had that positive in the sense of it's allowed me to still live life normally, and so there can be that sort of social interaction can't there, not necessarily with just direct colleagues, but you know, with wider people that you*

> *work with, and I do think, I do think if I didn't work I might lose my sense of purpose a little bit, and I sometimes think like I've worked hard to sort of get to a stage that I'm at, and I don't feel like I could just throw it away, so I think it still does give me that sense of identity and purpose." Winifred*

This includes connecting socially, having a purpose, and feeling a sense of self-worth. Willow feels that without employment, not only would she feel she was wasting time on meaningless activities, but it may have implications for her mental wellbeing. Wayne reflects a similar position, feeling that work allows him to keep his "*head above water*".

> *"I think it's pretty important, because it gives me like a purpose, which you know, you always want a purpose in life, because if I wasn't working, like I said, I'd just be in bed doing nothing, and wasting my life away and I think if I didn't get the job, I may've started to get a bit of depression." Willow*

Irrespective of health issues, work provides meaning. Beyond traditional positive resources work provides, such as self-worth and sense of purpose, participants also considered the demands of work and the potential benefit that work provides a sense of challenge. Wayne describes his decision to change careers, not due to his MS, but simply because he was not feeling challenged by the roles he was doing anymore. In this case, meaningful employment is about being challenged enough through work. Once there is no challenge to learn something new, the job becomes boring. William considers a similar phenomenon of what he pertains to as positive stress:

> *"…I think stress is an interesting one because it's not that you can necessarily alleviate your stress, it's not very helpful to say that, but I think you can try and manage stress. I don't really know enough about the kind of clinical definitions of stress because I think it kind of keeps you going and the medical world seems kind of pretty unified that stress is a bad thing as well. So yeah, I was listening to someone on a kind of podcast a couple of weeks ago talking about public speaking, we talked about that briefly before, and they were saying how the, that nerves before you go on stage or whatever you're doing, that they just see that as well that makes me feel alive because it's like wow I'm about to go and speak to a hundred people, that's a, yeah, fucking hell, that's, turn that into a positive, it's like I'm lucky to have that horrible feeling." William*

Despite engagement in paid work providing purpose, participants considered the importance of paid employment for allowing them to pursue a meaningful life beyond work. For example, some participants note that family and children have been a motivation to continue working. However, Winifred points out that retirement from work can be a meaningful time in which a person can reap the resulting rewards of work and enjoy other such aspects of life.

For Winona, the flexibility of her employer and workplace adjustments have allowed her to pursue a meaningful life in addition to her paid work.

> *"People often ask me do I find working from home isolating. And I don't, the reason being is, because of the nature of my condition, actually being in the office would be isolating for me, because I would, I would often be too exhausted*

> *to actually want to socialise with anybody in the office. I would literally, I would go in, get the job done, and come home and not even really wanna talk to anyone. And then I would just be home, I'd be exhausted, and I wouldn't then be able to go and do things, for example, in the evening. Whereas working from home has meant that I have a life outside of work, and it's actually made me more social because I'm able to, you know, adjust the way that I work and get the rest when I need it…" Winona*

Thus, it is important that work is meaningful, but also that work fosters a meaningful life overall.

Theme 3: Social Value; Sub-theme 3: Feeling Valued as a Worker (macro: cultural level)

Those who felt happy and secure in their job expressed feelings of being valued as a good worker, through confidence in their skills. Feeling valued could also be about feeling a sense of responsibility at work.

> *"…I feel like if I'm not in work, or if I gave up work that I'd be letting him down as well, because I know there's times when I have had sort of a period of time off work and that everything automatically gets shoved across to him, and not because we're together, just because we work in the same sort of team structure, so people just expect that he will pick that up." Winifred*

However, for employees who do not feel valued as workers, this can lead to feelings of resentment at work.

> *"…why should I take a cut in wages because I've got MS? It's just totally unfair. I, I can't compete to the same level as able-bodied people and I think my employer, particularly the HR, needs to take people, such as MS, Parkinson's, with cognitive issues, out of the performance related pay. Because it, you know, otherwise, we're always going to suffer and it's basically, you're having to, you're still having to do the same work. And then you start to feel resentful." Wilma*

Wendy considers that for PwMS, not feeling valued at work may be a result of interactions being negatively focussed rather than positively focused.

> *"…so I think that's the key thing with HR, you end up so often talking about negative experiences, or negative reactions, that it's very hard, everyone seems to forget about all your positive elements…" Wendy*

Theme 4: Togetherness (meso: organisational level)

Experiences of MS in the workplace also seemed to be influenced by social relations, whether this was a team mentality or a feeling of 'togetherness'. Those with particularly positive experiences usually accounted them to feeling that their co-workers were their friends, and people they could trust or rely on.

Togetherness includes two sub-themes which capture the distinct polarities an individual may experience: *Social assurance* and S*ocial aggression*. While employees may experience a range of interpersonal relationships stemming from both types, the occurrence of one would often take precedent as the overarching perception of the workplace.

It is worth noting here that this theme is relevant in the context of paid employment rather than self-employment. That said, for Wallace, the interview highlights that a sense of togetherness may exist on a macro-level, with perceptions around how societal structures can offer support and security in relation to employment.

> *"You know, you accept that in self-employment you are, that's exactly what it means, you are self-employed, you are self-supporting. If I'd been employed, maybe things would have been, I'm sure things would have been different, but I'm not, so I've never felt the need, you know, to go looking for help in that direction, because I've managed to stay functional and be able to carry on doing what I've been doing professionally for a long time" Wallace*

Theme 4: Togetherness; Sub-theme 1: Social Assurance (meso: organisational level)

Social assurance includes feeling a mutual trust and respect with others. One participant describes a strong positive sense of togetherness with her co-workers:

> *"…I can talk to them, just like a friend that I sort of go out for a drink with, do you know what I mean, like that's how personal it is, and you know, we can talk about our lives, and our hobbies and stuff…" Willow*

Willow's interpersonal relationships with her colleagues and managers goes further than a broadly polite civility; they are comparative to friends. This feeds into her sense of security in the workplace. Willow feels assured that should she need to, she can ask for help or accommodations, and the company will "*do anything to support [her]*". In response, she also wants to be a good employee for the company. She notes feeling respected, even in the context of a hierarchical structure at work.

Those experiencing a high level of social assurance in the workplace seemed to have less anxiety in relation to their work. For Wayne, many of his interpersonal interactions made him feel supported and validated regarding his MS. While he notes a lower frequency of support interactions with a new manager, Wayne affirms that his co-workers offer regular social support and assurances.

> *"I mean they've just been so good, all working together and looking out for me, you know? Make [sure] you don't do that, make sure you do this, make sure you at least have a sit down for five minutes in between your clinics sort of thing and, you know, if I do go into the staff room for a sit down nobody says anything. They'll just be like, 'You alright?' 'Yeah, just need five minutes,' 'Yeah, fair enough.'" Wayne*

Thus, it seems that social assurances at work can act as a key resource for PwMS, whether from managers or co-workers. Social assurance may provide a sense of validation at work for PwMS. Indeed, social assurance is not necessarily defined by feelings of friendship; Wendy points out that a key aspect of feeling socially secure at work is a sense of advocacy. Interpersonal trust also featured in several participant dialogues; participants that held positive interpersonal trust beliefs about their employer or manager seemed to feel more secure in their job. For Winona, she feels that her employer is understanding and flexible around her work needs, and that there is a mutual trust and respect around flexible working styles.

> *"He's very understanding, he, you know, he's got kids. He often has to take time off because, you know young kids [...] he very much takes the attitude… as long as the work gets done, he actually doesn't mind…" Winona*

While Winifred considers her daily interactions and interpersonal relationships with colleagues have kept her motivated to stay in work, it is the policies at her workplace that offer a sense of security. However, a key challenge for Winifred was the *authenticity* of social support from her manager.

> *"…so he'll say to me in my one-to-one, "Right, this is what I have to do, this is what happens to me, so [Winifred], how are you?" and you're like, mm, but then I'll be honest with him and I'll say, "Do you know, I'm not really having a great time at the moment, I'm feeling a bit stressed, I'm feeling a bit overwhelmed," and "Right, okay, yeah, I am as well, there's just so much to do isn't there, and there's so much work on, yeah, I think we're all feeling that," so there's never like an appreciation of how you're… so he asks the question, but doesn't listen to the answer, and he does that like in terms of my MS as well. So he'll ask me how I'm feeling and I'll tell him, and he tries to sort of go, "Yeah, I were feeling a bit crap as well last week," [both laugh], so he's just not helpful…" Winifred*

A positive sense of togetherness is important to feeling secure and supported in the workplace. Unfortunately, PwMS may also experience an opposite phenomenon: *social aggression*.

Theme 4: Togetherness; Sub-theme 2: Social Aggression (meso: organisational level)

Whilst legislation exists around direct discrimination, participants experienced more nuanced forms of discrimination through *social aggression*. Snide comments, or 'making an example' of the individual, in order to bring them down socially were behaviours experienced by some participants.

These social divisions can create an environment of insecurity and anxiety for the person with MS. Despite trying to be proactive and open in her communication with her employer, Wendy was met with inappropriate level response, which did not feel helpful to her to continue working.

> *"…I'd told them my experience of it but I'd also brought literature for them, you know, working with my MS, employers and MS and all this kind of thing and I'd always said, you know, "Please if you have any queries, if you have any questions just ask me," but they did peculiar things, like this very demonstrable risk assessment of me in the building, which felt quite singularising, you know, like highlighting our disabled person, and then like it was actually the HR manager who went around with a role of gaffer tape to tape down all the cables so that I*

> *couldn't trip over them, and I was like, do you need to be doing this while I'm here." Wendy*

Humiliation like this occurred multiple times in Wendy's experiences, and there was an evident social power hierarchy being displayed. It was not just Wendy's employers who seemed to want to vilify her. Colleagues displayed behaviour which she likened that which occurs in school playgrounds between groups of girls. This form of bullying has more a psychological impact than a physical one. Wendy was not the only participant who experienced clear bullying in the workplace.

> *"Well, I had to move from that team, because it was untenable, which it's a big organisation as well, so it was untenable for me to work with those few women anymore, and the union had said there was evidence that I was being picked on, so, because I'd been to the union, and then, but because I'd moved teams, the union didn't pursue it. And I actually wanted to lodge an official grievance so that those women know, knew how they'd made me feel. So I felt that I wasn't adequately supported, because they said "well what, what do you want to get out of this, do you want to move, you know, you've already moved teams, it's quite..." but that wasn't what I wanted, I wanted acknowledgement I had got bullied, that they know, and I just felt that I was ignored at that time." Wilma*

False assumptions appear to result in stigmatised perceptions of PwMS. For example, some participants were accused of being drunk when their balance was not good or accused of being lazy due to their fatigue. It seems that employers and co-workers who lack understanding or knowledge of MS initially assume moral blame. One such example being Winifred's experience with a new line manager, who has associated her MS flare up with a party she attended several weeks ago.

> *"…because my partner also works on the same team as me, and he actually said to him yesterday, "Oh, how is [Winifred], is she okay?" and he said, "Oh she's okay, you know, I think working from home helps," and he said, "Oh, it'll be all this partying she's been doing," because he knows, I were at a colleague's wedding sort of a couple of weeks ago, and he's associated me doing things outside of work with how it's then impacting on work, as if... and like that's the first wedding or social occasion I've been to probably like in six months, but he's automatically linking it to, oh, almost as if like oh it must be my fault that like I am like I am now, because it's too much partying." Winifred*

In this case, this may have been a naive lapse in judgement on the part of the line manager. However, social aggression in the workplace can present significant negative psychological outcomes for PwMS.

Theme 5: Adjustment Process (micro and meso levels)

MS employees seem to find themselves juggling many factors in an uncertain time; navigating their condition which may continually present new or changing information about how their body and mind are now operating is an ongoing process of adjustment and learning. In addition to this, their employer may lack understanding or appropriate policies to help guide them through successful continuation of paid employment, thus adding to the mental workload of managing their MS.

Theme 5: Adjustment Process; Sub-theme 1: Managing Uncertainty (micro: personal level)

Receiving a diagnosis of MS can be an emotionally difficult time. William found that the period immediately following his MS diagnosis highlighted the level of uncertainty in the condition. This uncertainty did not fit well to his identity of being a planner and presented a feeling of not being in control. A coping mechanism was to take control over the factors that he could, including disclosure of his MS.

> *"…I felt there was no choice but to be clear with my line manager and the boss of the agency due to the time off work, so I told them about the diagnosis but I was also very clear with them that I didn't want them to tell anyone else. And I think part of that was down to, um, the need to maintain some level of control. That was like a period where every question I asked was answered with either "we don't know" or "it depends" and I was aware that once you tell, I suppose I knew enough early on to realise that if you tell people you've got a diagnosis of MS you can't un-tell them." William*

Diagnosis of MS appears to cultivate an increased appreciation of life as well as awareness of fragility as a response to diagnosis.

> *"Well, I'm 41 now, so where am I going to be in another five years, you know? Is my next lot of medication going to help me for another ten years or is the medication going to help me to a certain degree but the MS is still going to get the better of me? You know, it's always in the back of my mind that I have got this condition and every morning I get out of bed's a bonus. You know, I'm not stupid, I know that if I can wake up at six o'clock and go downstairs and watch a bit of telly and get ready, you know, for work before I start then that's going to be a good day, you know?" Wayne*

Wayne highlights the uncertainty MS brings, and how this uncertainty can always play "*in the back of my mind*". He is aware of the fragility of life, recognising that "*every morning I get out of bed's a bonus*". This extract also shows how he has adjusted his expectations to fit around his MS, in that so long as he can get up and get ready for work then it will be a good day. The parameters of "good" become wider ranging when there is an awareness of how quickly things could become worse.

PwMS seem to display some similarities with people who have experienced trauma, in their awareness of life both in terms of appreciation for it and fragility of it. Some experienced this in a positive way, describing themselves as 'lucky' for the hand they had been dealt, expressing gratitude for what they had, and savouring where they were at now. One example, Wallace said "*I've been very fortunate, so, you know, I appreciate that every day, the fact that I can get up and carry on is good*". Others had developed a level of anxiety related to their health and ability to work. For example, Winifred notes that *"…it's always that fear that like whilst I can work I want to work…"*. Participants noted coping strategies to the uncertainty of MS. For Wilma, focusing on factors within her control, such as healthy lifestyle choices, was a way to manage the uncertainty and improve her experience of MS.

> *"I just try and keep myself as healthy as I can, so that it doesn't happen. But there are no guarantees. There's no guarantee that I'm not going to wake up tomorrow morning and suddenly find that I can't walk in a straight line, I just don't know. And I have to try not to think about it." Wilma*

However, Wilma also accepts that there will always be an uncertainty to her condition. Wallace considers that work is helpful to distract from ruminating over the uncertainty of MS.

> *"… you can't live every day as though you think it's going to be your last, you do have to keep, you have to have a little bit of an eye on where things might go and try and have a little bit of a plan in the back of your mind, but you've, you need something to keep you moving forward, and work is a good, work's a good discipline, that's the word I'm looking for, discipline, it's a good discipline, because it's something you, it gives you order, it gives you structure to the day, it gives you a physical and mental challenge because you have to plan what you're doing, you have to carry out what you've planned, there's a physical demand to getting something done, and then at the end of it, when it works, hopefully, you get the personal satisfaction of having, particularly if you're doing it, you know, if you work for yourself, it's you, there's only you." Wallace*

Further, Wallace suggests that having a plan is a good way to reduce uncertainty in other domains.

Theme 5: Adjustment Process; Sub-theme 2: Learning about MS (micro: personal level moving into meso level)

When asked about their experiences of diagnosis, most participants had previously held limited knowledge about MS or how it could affect them. Those with some knowledge were mostly aware of potential mobility issues that can develop. It is a steep learning curve and can be overwhelming for a newly diagnosed individual to be presented with so much information as well as so much uncertainty about what it means for them.

> *"I don't really know how I felt, I just, I didn't know how it would affect me and how it was going to go on, and initially think "oh, am I not going to be able to go to work anymore?" and "I might end up in a wheelchair"." Wilma*

In addition to learning about this neurological condition generally, people with MS have to learn how it impacts them individually. This can also be a challenging learning curve, as individuals must adjust their previous knowledge of the self.

> *"Yeah, well, I think if I did try to run I'd just end up tripping over myself, I don't think my legs would have the coordination now to, sort of, do that sort of*

> *thing. Whereas, as I say, I used to be able to run on a treadmill for ages and, you know, it wouldn't have any effects afterwards." Wayne*

The process of learning about MS may require time, and trial and error. Wallace notes that he has been able to learn what jobs he can manage alongside his fatigue and has adjusted his work around this.

> *"I suffer with fatigue, I have to be more conscious of what I take on, the size of projects, how long they're going to take, how difficult they are to complete and so on, so, yeah, I'm more conscious of that now than I was, certainly in 2012 when I was first diagnosed…" Wallace*

Theme 5: Adjustment Process; Sub-theme 3: Managing Change (meso: organisational level)

There was some conjecture about who had what responsibilities in terms of managing paid employment for someone with MS. Those from a larger organisation seemed to have more positive experiences in regards to a clear policy or procedure to guide them through managing their MS and work. Smaller organisations did not often have capacity to manage the process of making reasonable adjustments, some not having any explicit HR staff in place.

> *"…my employer didn't really have a clue, didn't know how to treat me. That's not suggesting they treated me in any way incorrectly, it's just they didn't know how to deal with me, which I fully understand." William*

This lack of preparedness from William's employer does not appear to be malicious or discriminatory in itself; notably, those who conveyed a sense of mutual trust with their employer were evidently less aggrieved by such events. Regardless, it can create additional pressure on the employee during a time that is likely already stressful and energy-depleting. For those that already did not feel particularly supported or secure with their employers, this seemed especially taxing.

> *"...fatigue is a daily problem, alright, me having to like handhold you through your responsibilities as an employer, I don't have the energy for this, I certainly don't have the enthusiasm for this, but if I don't you're just being shit and I'm having a worse time because of it…" Wendy*

Wendy points out during her interview that it would be unreasonable to expect employers to have knowledge of the vast possible conditions that humans can develop. Rather, the attitude to learning about MS may have been more useful in helping her to navigate strategies at work. However, the burden of navigating adjustments often appears to fall on the employee, who, having now had some experience of uncertainty, is perhaps considered by their employer to be more equipped to manage this new unchartered territory.

There are arguable benefits and drawbacks of this. It can be empowering to allow the employee to dictate their own adjustments. However, this can add further burden to an already uncertain and challenging context. In addition to seeking reasonable adjustments, employees may find that adjustments set by their employer are not effective in practice. Winifred's employers have allowed her flexibility in her working hours, to give her opportunities to rest throughout the day. Rather than this adjustment being helpful for Winifred to engage successfully in her work, she feels a sense of guilt for the mismatch between her contracted hours and actual hours worked. Thus, she tries to compensate this by completing the time later in the day, which contributes further to energy depletion.

> *"…then I just think if I rest now and then the kids come back later on then I'm not going to get as much work done as what […] I am just adjusting the work pattern, but still doing the same hours in the day, but probably not doing myself any favours because I'd then work till like seven at night, and then struggle to sort of wind down…." Winifred*

In this scenario, Winifred is trying to adhere to concepts of an 'ideal' worker in the amount of time she is giving to her work, rather than the output of her work. This is perhaps an unhelpful way to measure the value she is providing through her work. An open dialogue is essential to ensuring that adjustments to do not cause further stress in practice. Winona's employers were able to implement a similar adjustment, but more effectively for her.

> *"…they give me time off for my medical appointments, and I don't need to make up that time. 'Cause I know a lot of companies, if you've got to take off, if you've got to take time off for medical appointments and it takes the end of them say an hour, they'd rather take it out of your annual leave or take time in lieu and make it up, and things like that. My, my company doesn't." Winona*

Discussion Point: Financial Planning

As well as managing changes due to MS impact and managing adjustments in work, PwMS may have to consider the financial impact of reduced working hours or increased living costs due to their MS.

> *"… [My manager] wanted me to cut my hours and I didn't want to because of the money. But she was like… what she was scared of is if I kept doing it until 4:00, that I was still overdoing it and I'm still going to be really sick every other day…" Wayne*

Participants found themselves having to make a decision between working at the detriment to their health or reducing work but it impacting their financial situation. Unfortunately, for some, reduced finances did not feel feasible. Wilma describes that she feels unjustly disadvantaged, financially, due to her employer's response to her MS.

> *"…why should I take a cut in wages because I've got MS? It's just totally unfair. I, I can't compete to the same level as able-bodied people and I think my employer, particularly the HR, needs to take people, such as MS, Parkinson's, with cognitive issues, out of the performance related pay." Wilma*

A reduction in wage can consequently impact future financial planning, such as retirement planning. Winifred notes that she is aware of others who have been unable to contribute to their pensions due to an insufficient wage.

> *"…I know a lot of people that have had to stop paying the contributions because they've not been managing sort of on the wage that they're getting anyway…" Winifred*

Discussion

This study seeks to explore how PwMS, relevant health professionals and employers work together to facilitate job retention in MS. This subset seeks to understand the barriers and facilitators to maintaining work as experienced by PwMS in the workplace.

The objectives were to interview 6-8 PwMS in paid employment for a minimum of 2 years, to understand their employment experiences that may influence job retention. Five key themes were identified via critical grounded theory analysis: *Social Role, (Il)legitimacy Processes, Social Value, Togetherness,* and *Adjustment Process*. These themes describe the pragmatic facilitators and barriers, as well as the social structures which contribute to workplace experiences for PwMS. Findings are discussed in the following paragraphs with respect to the extant literature and theory.

While each main theme has some involvement at the meso-level, as would be expected given the focus of this research, some operate much more exclusively within this meso-level. The theme *Togetherness* includes two divergent sub-themes of organisational interactions PwMS experience in the workplace: *Social assurance* and *Social aggression*. Some main themes describe a similar mechanism but operating independently at each level of the socio-economic model. For example, the theme *Social role* is grounded in the concept of fitting to an expected identity. At the micro-level, this is shown by *Social identifications*: those factors that we consider account for our behaviours and beliefs. At meso-level, *Social roles* arise in the sub-theme of the 'ideal' worker. The final, macro-level sub-theme of *Social role* is *Disability box*, which conveys societal assumptions of disability. Similarly, *Social value* deals with the value of paid work as a mechanism operating at each of the socio-economic levels.

This analysis identified two processes that people with MS enter into, beginning at either onset or diagnosis. The *(il)legitimacy process* reflects that by which people with MS must continually validate, legitimise and reaffirm their needs and experiences. This process occurs at organisational level by which the individual is often having to negotiate adjustments, manage expectations and open themselves up to vulnerability in potentially socially insecure settings. Another process is the *Adjustment process*. This begins generally with learning about MS, which is a substantially individualistic condition. This part of the process is usually the beginning of an ongoing experience of uncertainty: it is uncertain how or if the condition will progress. It is uncertain if drug therapies will help. It is uncertain when or if there will be another relapse. Managing this uncertainty plays a major role in the lives of people with MS. In addition to having to develop strategies to try to manage this uncertainty, people with MS also find themselves having to navigate changes to their work role. This could be through establishing any adjustments needed, educating employers, or determining changes (or lack of) to their capabilities.

Theme 1: Social Roles

Collective self-identities are those associated with belonging to socially relevant groups, for example, organisational teams or social class systems. Johnson, Chang, and Yang (2010) consider how these chronic self-identities can impact wellbeing and motivations in the workplace for individuals. Collective self-identities may affect norms and goals for PwMS, and therefore these may impact work outcomes and impact of interventions.

Participants' self-assignment to social roles is consistent with social role theories, which pose that people seek to behave consistently to social definitions of their perceived roles (Katz & Kahn, 1966; Sluss, Van Dick, & Thompson, 2011). Individuals in society make use of various social identifications which contribute to their role at the different levels of interactional transactions. British, Working-class, Disabled, Young: these are all constructs of being through which an individual can identify how they are different or the same as those around them. This social role can act as a set of guidelines of how to interact socially. When social role correlates positively with an individual's own interpretation of self, this can have beneficial consequences. However, if there is conflict between the individually perceived role and that which society deems fitting, this can be at best frustrating and at worst deeply distressing. In this case, role theory does not fully explain the experiences of PwMS; where socially assigned roles, such as 'disabled', are given, individuals may resist or resent such roles. This can create a social discord that leads to challenging interpersonal relations in the workplace.

Goffman (1968) outlines how society discredits and stigmatises people with disabilities through the act of "Othering". Although PwMS may not identify as disabled, the conflation of MS and disability can see them experience the same phenomena befalling people with disabilities. Thus, literature that seeks to understand the interaction between social mechanisms and disability may be relevant to PwMS. However, because MS often does not comply with social perceptions of what disability ought to look and behave like, PwMS may face an additional form of stigmatisation for not conforming to this social role. Link and Phelan (2001) argue that "*there is a social selection of human differences when it comes to identifying differences that will matter socially*" (p.367). This process forms the beginning of stigmatisation and social norms. Social norms are the shared beliefs as to how people ought to behave (Stafford & Scott, 1986).

Fine and Asch (1988) describe five key assumptions able-bodied people make about disability, including that disability is central to the person's self-definition. However, through the sub-theme of *Disability box* we see that this is not the case for PwMS. MS makes up only one element of a vast, complex identity for individuals. Such assumptions are potentially based on able-bodied experiences of illness; able-bodied persons have the privilege of pausing their normal daily routines due to illness, as this is a temporary state with an expected trajectory of eventual improvement. People with MS cannot necessarily afford to put their life on hold for this uncertain and often fluctuating chronic condition. Further, participants of this study felt that employers or co-workers might over-emphasise their MS. Grytten and Måseide (2006) found a similar phenomenon; such social responses can contribute to negative experiences and barriers in the workplace for PwMS.

In addition to social identifications and disability constructs, cultural expectations of the '*ideal worker'* may influence how PwMS experience the workplace. Meeting pragmatic duties of the job can be made more challenging by the expectation to function within this '*ideal worker'* role. Organisational structures conceptualise the 'ideal worker' as a person (most usually a male) who is unwaveringly available to work and is not detracted from work duties by way of home and family life (Acker, 1990; J. C. Williams, 1999). The 'ideal worker' concept in this sense is already an unreasonable expectation, even of the most 'able-bodied' individual. However, here, we see that the requirement may go beyond long hours (when) and an onus on the employee to be flexible to travel or relocate (where). PwMS discussed social expectations for *how* an employee completes their duties. This includes factors such as routine working hours, home-based working and even activities outside of work. PwMS felt stigmatised where they did not conform to these perceived norms. Employees can find themselves being expected to go beyond their duties of work, even if it means working unpaid overtime. This may see PwMS at greater risk of presenteeism and the adverse health impacts of this; presenteeism refers to the phenomenon of working during periods of illness (Johns, 2010). These kinds of expectations within UK work culture may not be limited to PwMS but may disproportionately disadvantage employees with chronic health conditions (Foster & Wass, 2012).

Challenges in the workplace for PwMS due to conflicts between self-identifications and socially assigned identity norms might be understood by social exchange theory (Emerson, 1976). Social exchange theory suggests that exchanges between two parties carry a set of obligations and expectation for reciprocal transactions between these parties. However, Homans (1958) asserts that transactions can include those of symbolic value such as approval and prestige. Stigmatisation and "othering" signal the beginning of a negatively focused exchange process, by which PwMS are penalised for "breaking the rules" of implicit social expectations. This occurs on multiple levels; simultaneously PwMS do not conform to the label of 'disabled' and 'ideal' worker norms.

Kmec, O'Connor, and Schieman (2014) found that workers who violate ideal worker norms experience unfair treatment, such as penalties or stigmatisation, upon return to work. Interestingly, Kmec et al. (2014) found that men were less likely to perceive unfair treatment, suggesting a difference in how men internalize worker norms. It is notable that in this study, women more prominently experienced negative perceptions of invalidation at work. On the other hand, it was more often men that discussed feeling valuable through work. One male participant discussed the impact on his self-esteem for no longer being able to work conventional full-time hours; in the UK, full-time work is commonly 37.5 hours. Thus, this has become a normalised expectation of working. However, average hours worked can vary across different parts of the world, which may be reflected in societal attitudes around the concept of the ‘ideal worker’. Gender differences in how PwMS experience social transactions and worker norms in the workplace may be an informative area for future research.

Limited societal assumptions of disability and the construct of the *Ideal worker* are not congruent. This is even more disrupted by the fluctuating, uncertain nature of MS, which does not fit an easy-to-follow pattern of progression or deterioration. However, it is interesting to consider that these limitations may be less to do with the individual’s capabilities so much as the environment in which they are trying to navigate. The assumption that disability is a feature of the individual rather than the result of an environment created for the 'able-bodied’ is inherently ableist. For example, when a fish in unable to swim on land, we do not consider the fish disabled. As, such, (Foster & Williams, 2014) review ableist organisational norms can have negative impact on employment outcomes for people with disabilities. The ‘glass door of disability’ as mentioned explicitly by one participant (but alluded to by others) is a concept that Roulstone and Williams (2014) explore further, and term ‘Glass partitions in disabled workers’.

Haynes (2012) explores the concept of physical capital in the workplace, with gendered embodied identities serving as social norms that can influence work outcomes. For PwMS, having the ‘correct’ embodied identity can be problematic and lead to stigmatisation in the workplace. However, rather than being marginalised for not meeting norms of ‘professional embodiment’, PwMS may face stigmatisation and scrutiny for not meeting norms of ‘disability embodiment’. Participants noted that if they appear ‘healthy’ or pursue physical identity characteristics (examples such as body piercings) that are not in line with social perceptions of the ‘disabled body’, the reality of their illness and adjustment needs may be queried or criticized. The resulting invalidation processes are discussed next.

Theme 2: (Il)legitimacy Processes

PwMS face illegitimacy as a form of stigma due to MS not conforming to the embodied expectations of disability (Grytten & Måseide, 2005). Validation is an important facilitator to positive work experiences for PwMS. Participants of this study noted the interrelationship between the invisibility of MS and invalidation experiences. Thus, PwMS are faced with difficult disclosure decisions.

Disclosing MS can mean putting out an identity of ‘disabled’, which comes with a risk of stigmatisation. Contrarily, Goffman (1963) notes that people with invisible chronic illness may choose to disclose in order to avoid stigmatised perceptions. Indeed, disclosing may be a useful tool to gain more understanding and validation from others in the workplace (Norstedt, 2019). Disclosure may also be used to gain a sense of control in an uncertain chronic condition such as MS (Bosma et al., 2019). However, people who do disclose feel that they are treated differently; thus, people with invisible disabilities are in a vulnerable position regarding their disclosure at work (Norstedt, 2019).

One participant described an explicit process of legitimisation that led to her feeling vulnerable. Her description bore resemblance to the Interpersonal Process Model of Intimacy (Reis & Shaver, 1988). This model outlines how intimacy is developed through social transactions of sharing personal information. However, for PwMS, sharing personal information may be required outside of a desire to develop interpersonal intimacy, which can have a negative influence on the interactional dyad. Where the individual receiving the information does not offer a relevant response, feelings of alienation and distance may occur. Legitimisation can also be considered in relation to social exchange theory (Emerson, 1976). Social exchange theory denotes that a series of actions generate expectations or obligations. However, reciprocity in the social exchange is not adequately balanced where PwMS are required to disclose personal detail in the workplace. In a recent review of social exchange theory, Cropanzano and Mitchell (2016) explore how the expectation for reciprocity appears to be a universal principle with implications for perceived organisational support. However, Cropanzano and Mitchell (2016) also conclude that the degree to which this principle is prioritised can vary across individuals and cultures. Finally, equity theory posits that relationships are satisfying to the extent that contributions are perceived to be balanced (Adams, 1965). Thus, for PwMS, perceived social inequity may make continuing work psychologically challenging where the individual with MS must continually expose vulnerabilities to be legitimised in the workplace.

Some participants noted the validating power of disabilities related legislation. However, Foster and Fosh (2009) argue that current legislation designed to protect people against disability discrimination in the workplace is open to significant interpretation which may be to the detriment of employees with MS. Indeed, management of reasonable adjustments appeared to be up for negotiation and interpreted in line with organisational expectations rather than standardised procedures. How these negotiations unfold seems to be linked to interpersonal trust relationships, explored further on in the context of *social assurance*.

Finally, this analysis shows that even after disclosing their condition and acquiring adjustments, PwMS must continue to re-affirm the impact of MS. While management strategies are useful in reducing burden of MS, the individual may continue to be challenged by background symptoms and fluctuations in their condition. Invisibility of MS has a key role to play in this.

Theme 3: Social Value

This analysis highlights the ways in which individuals with MS can acquire social value: feeling valuable through doing work, getting value from the work, and feeling valued as a worker. Professional occupation forms a substantial part of how an individual makes sense of their life story (Linde, 1993).

Social capital theory outlines how value can be elicited from interpersonal relationships and their capacity for achieving desired outcomes (Seibert, Kraimer, & Liden, 2001). Being able to engage in paid work may present as a means of attaining a valued social status. Hall and Widén-Wulff (2008) demonstrated through a series of case studies how a social capital framework might be useful in explaining drivers of social exchange relationships. In a group with high social capital, the increased level of trust and perceived support led to greater information sharing with decreased monitoring but increased likelihood of reciprocity. For PwMS, social capital may be an important factor in promoting positive exchange relationships in the workplace which in turn promotes a sense of value through paid work,

Kielhofner’s (2008) model of human occupation outlines the interplay between occupation and identity. Occupational identity is important for individuals to engage meaningfully as part of society (Jakobsen, 2009). However, Phelan and Kinsella (2009) argue that theories of occupational identity hold assumptions of the individual as central to identity formation, failing to recognise the potential influence of the collective. For PwMS, self-identity and social identity may not be congruent therefore this becomes problematic.

Feeling valued at work has positive implications for self-worth (Sluss, Klimchak, & Holmes, 2008). Further, the interpersonal dynamic between managers and employers can have important consequences for the employee’s perceptions of self-worth (Deci, Connell, & Ryan, 1989)

Beyond traditional positive resources work provides, such as self-worth and sense of purpose, participants also considered the demands of work and the potential benefit of work providing a sense of challenge. How this plays out may be determined by theories of social identity. Specifically, regulatory focus theory suggests that people are driven by either a need for growth (promotion-focus) or security (prevention-focus) (Brockner & Higgins, 2001). Thus, individual regulatory foci may impact how value is extracted from workplace challenges.

Theme 4: Togetherness

Sense of togetherness could be positive (*social assurance*) or negative (*social aggression*). *Social assurance* seemed to be influenced by interpersonal trust, feelings of authenticity, and security aided by organisational policies. Relational trust is formed in response to interpersonal interactions rather than an overarching belief system (Zaheer, McEvily, & Perrone, 1998). Participants in the present study who held good relational trust relationships with their managers also felt assured and secure in their work setting. Zaheer et al. (1998) found that in high trust conditions, exchange partners are less likely to rely on structural safeguards. Winona discusses how she is aware of, but does not require the utilisation of, legislative safeguards for her in the workplace. On the other hand, Wilma has limited trust in her employers and therefore pursues more official, documentable routes to ensure her own protections. Further, Zaheer et al. (1998) note that in high trust settings individuals may give less focus to blame-assignment but focus instead on finding a mutually beneficial outcome. In the theme, *social aggression*, an opposite effect is seen; blame and responsibility become a higher priority. The sub-themes of *Social assurance* and *Social aggression* are consonant with more recent iterations of social exchange theory (e.g., Cropanzano, Anthony, Daniels & Hall, 2017), in that exchanges can be distinguished as hedonically positive or negative, with positive exchanges instigating positive reciprocal action and vice versa.

Williams (2007) explores the interaction between trust and threat regulation, with higher trust reducing emotional threat response. Finally, trust may help to reduce uncertainty about the future which may be particularly helpful for PwMS (Lewicki & Bunker, 1996).

Theme 5: Adjustment Processes

Adjustment to MS and work includes three key sub-themes: *Managing uncertainty*, *Learning about MS* and *Managing change*. While the latter may include interactional exchanges influenced at organisational level, *Managing uncertainty* and *Learning about MS* generally occur at the individual level.

Self-management of illness is highly correlated to self-efficacy beliefs (Leventhal, Phillips, & Burns, 2016). Self-efficacy in PwMS is also linked to level of work instability (Ford et al., 2019). Thus, it is logical that PwMS who have higher success in managing their condition may be less likely to be at risk of leaving paid employment.

Self-efficacy may be mediated by interpersonal relationships, with positive assurances from close others influencing motivation (Bandura, 1982). Maurer, Pierce & Shore (2002) point to the expectancy-valence model (Vroom, 1964) to explain how this can occur in the workplace setting with organisational exchange relationships contributing to an expectation that the employee can meet a particular goal or task. The expectancy-valence model posits that individuals are motivated to achieve a goal where they believe that; 1) the effort will be sufficiently counterbalanced by the reward and 2) they possess the capabilities and tools to achieve the desired goal. Thus, organisational exchange relationships may also influence motivation to find strategies to manage MS symptoms alongside work. Exchange relationships include those at the interpersonal level (i.e., manager-employee relationships) and at the organisational level (such as perceived organisational support).

Frank (2013) describes three distinct narratives of illness: restitution, chaos, and quest. Restitution, which focuses on curing the illness, may be less applicable to PwMS. Chaos frames the illness as an ongoing experience without respite and is suggestive of negative coping mechanisms. The quest narrative is concerned with finding how illness can transform the individual. This latter narrative is explored in the context of an individual with MS by Vijayasingham (2018) and can offer a positive coping mechanism amidst the uncertainty that MS presents. On the other hand, workplace barriers and perceived dependence on others can lead to increased anxiety for PwMS (Butler, Thomas, Carolan, Silber, & Chalder, 2019).

Participants with MS displayed some self-narrative parallels with people who have experienced trauma, in their awareness of life both in terms of appreciation for it and fragility of it. Many described themselves as ‘lucky’ for the hand they had been dealt, and some talked about savouring where they were at now. This is possibly a response to the life-limiting nature of MS, and an increased awareness that the future is uncertain. Irvine, Davidson, Hoy, and Lowe-Strong (2009) also found that part of adjustment to MS involves an adjusted appreciation for life. Interestingly, Wayne appears to have developed a coping mechanism that has been studied in victims of severe accidents (Bulman & Wortman, 1977). Blame attribution is a mechanism to assign meaning to events, in order to come to terms with them. Wayne attributes self-blame to his MS diagnosis being a result of previous head-banging to heavy metal music.

PwMS discussed the reasonable adjustments they had negotiated in the workplace. To add to the uncertainty of MS, the responsibility of who should or can help alleviate workplace challenges was not always clear. This can put MSers in a position of limbo, feeling guilty or anxious for not being able to successfully manage their condition alone, but also feeling frustrated at not receiving adequate support. Although legislation places a level of responsibility on employers to mitigate challenges that may prevent someone with disability or chronic illness from accessing paid employment, PwMS appear to adopt the predominant burden in managing any necessary planning or implementation of required adjustments. PwMS find themselves simultaneously managing physical and psychological difficulties that MS presents while also coaching their employer through job retention strategies which they themselves may still be determining. This is not necessarily due to a malicious or uncaring employer, but can occur as a result of unawareness, inexperience or lack of suitable strategies in place to coordinate reasonable adjustments. Bachrach and Baratz (1962) assert that non-decision is an act of asserting power over a marginalised group. The shifting of responsibility by employers to employees with MS can be perceived as an act of non-decision by the employer, thus immobilising the employee, who lacks the power to authorise effective change to their situation. That said, Wendy points out during her interview that it would be unreasonable to expect employers to have knowledge of the vast possible conditions that humans can develop. Thus, it may be useful for managers to have a clear strategy to navigate appropriate individualised adjustments which permit the ‘expert patient’ to guide without undue burden.

Finding strategies to successfully manage or reduce their symptoms can be majorly beneficial to MSers who want to keep working at a level they feel satisfied with and can provide a sense of control amidst the uncertainty. These strategies could be medical intervention (DMTs), or they could be flexible working around symptoms such as fatigue. While flexibility can be a useful adjustment tool for PwMS to manage their work, Foster and Williams (2014) argue that flexibility can also be problematic for employees with disabilities. Flexibility may blur the boundaries between work and personal life, or workers who request flexibility can be perceived as uncooperative or uncommitted (Cech & Blair-Loy, 2014).

In addition to managing these adjustments, PwMS may find themselves re-evaluating their life goals and career aspirations. This may be relevant to theories of goal-adjustment and motivation (Bandura & Cervone, 1983). Future research and interventions should consider whether staying in work is preferable to the individual, and how to support PwMS in the process of leaving work should this become the priority.

Strengths and Limitations

This participant subset offers insights from a broad range of occupational backgrounds, including private, public, and charitable sector workers; white, blue, and pink-collar workers and full-time, part-time and self-employed. As such, the themes identified may be applicable to a wider MS population. Previous literature looking at employment experiences of PwMS has been limited in utilising voices from a limited sample, such as ‘white collar’ employees or ‘office based’ workers with MS (e.g. Kruger & Coetzee, 2019; Vijayasingham, Jogulu, & Allotey, 2017)

Unfortunately, due to time and resource limitations, this study does not adequately represent the marginalised voice of people of colour with MS. Despite evidence that black people may be at higher risk of MS (Langer-Gould, Brara, Beaber, & Zhang, 2013), the presentation of relevant candidates did not appear during recruitment to this study. Marginalised groups are less likely to participate in research for a number of reasons, and as such their voices often go unheard (Bhopal & Deuchar, 2015). Future research that specifically aims to target such groups is important.

Conclusions

Potential barriers and facilitators to paid employment with MS occur at multiple levels of societal organisation. Individual-level factors have been considered in the literature, but account for only a proportion of factors that can influence work outcomes for PwMS. Organisational and societal level factors can include a range of norms: disability embodiment, ideal worker norms, and social identifications. Social exchange theory (Emerson, 1976) is central in understanding how exchange interactions have a significant role to play in positive or negative work experiences for PwMS; employers who foster support, interpersonal trust and validation may be met with engaged, motivated employees with MS. On the other hand, where the dynamic between employee and manager or organisation is strained, this can create barriers and conflicts which lead to undesirable work outcomes for all parties. Further, social exchange theory offers a useful explanation to how social capital and empowerment processes may facilitate positive workplace experiences for PwMS.

Finally, managing MS should not be an individually assigned burden; employers may be aware of their legal responsibilities, but the practice of implementing reasonable adjustments may require a more individualised yet collaborative approach.

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Chapter 5: Analysis: People with MS No Longer in Work

Introduction

This analysis deals with the perspectives of PwMS who have left paid employment. To gain insight into barriers of continued employment for PwMS, it is important to consider the experiences of those who have left work. The experiences that improved workplace experiences, as well as factors that ultimately lead to cessation or work are useful in understanding how PwMS might be able to stay in work longer where they wish to. It is also important to consider the roles of life after paid employment and the retirement process in perceptions of employment and MS. Szinovacz (2013) emphasises the importance of considering the macro-, meso- and micro-level factors that contribute to retirement. The impact of MS may uniquely affect the experiences of retirement for this group.

PwMS are at higher risk of early retirement as soon as 5 years after diagnosis (Pfleger, Flachs, & Koch-Henriksen, 2010). Understanding contextual factors that may contribute to this could be helpful to people with MS who wish to stay in work. It may also be beneficial to provide insight that makes the transition out of work more manageable.

Method

Participants and Recruitment

Participants for this data set included people with MS who had left paid employment no longer than 12 months prior to interview. Six PwMS took part in research interviews, of which 1 was male. Average age of this group was 51.7 years. Two participants were diagnosed as relapsing-remitting MS, 2 had secondary progressive MS, 1 had primary progressive type and 1 participant had rapidly evolving severe MS. Occupations of participants covered a range of public and private sector roles, from various sized organisations. Further demographic details are provided in the methodology chapter.

Data Collection

Sampling was purposive. Potential participants were approached via local MS clinic, as well as utilizing online advertising for the study and research contacts such as MS charities. Further details are provided in the methodology chapter.

Semi-structured interviews followed an interview guide specific to this group (Appendix C.2). Broad questions about diagnosis experience and previous job roles were asked, followed by more in-depth questions about responses to disclosure, feelings towards work and thoughts on having left work. The interviewer probed for further detail to avoid assumptions and allowed periods of no questioning to allow the participant to consider and develop their answers, allowing the participant to navigate the topics according to their priorities. Interviews lasted between 58 minutes and 1 hour 41 minutes, with an average length of 1 hour 16 minutes.

Data Analysis

Data was analysed using critical grounded theory methods (Belfrage & Hauf, 2016). Further detail is provided in the methodology chapter.

Analysis and Model

Six main themes and 19 sub-themes were identified relating to PwMS no longer in work. The main themes are *Dispositional Properties, Adjustment strategies, Dis/Empowerment In/validation matrix, Social Relationships, Organisational Culture and Locus of Control.*

While these themes are specific to the non-working group, there is significant overlap with the working group. This is not unsurprising, given that the overall topics under observation are the same; barriers and facilitators to paid employment for PwMS. Thus, during interview, the non-working group will have considered their in-work experiences that preceded leaving work.

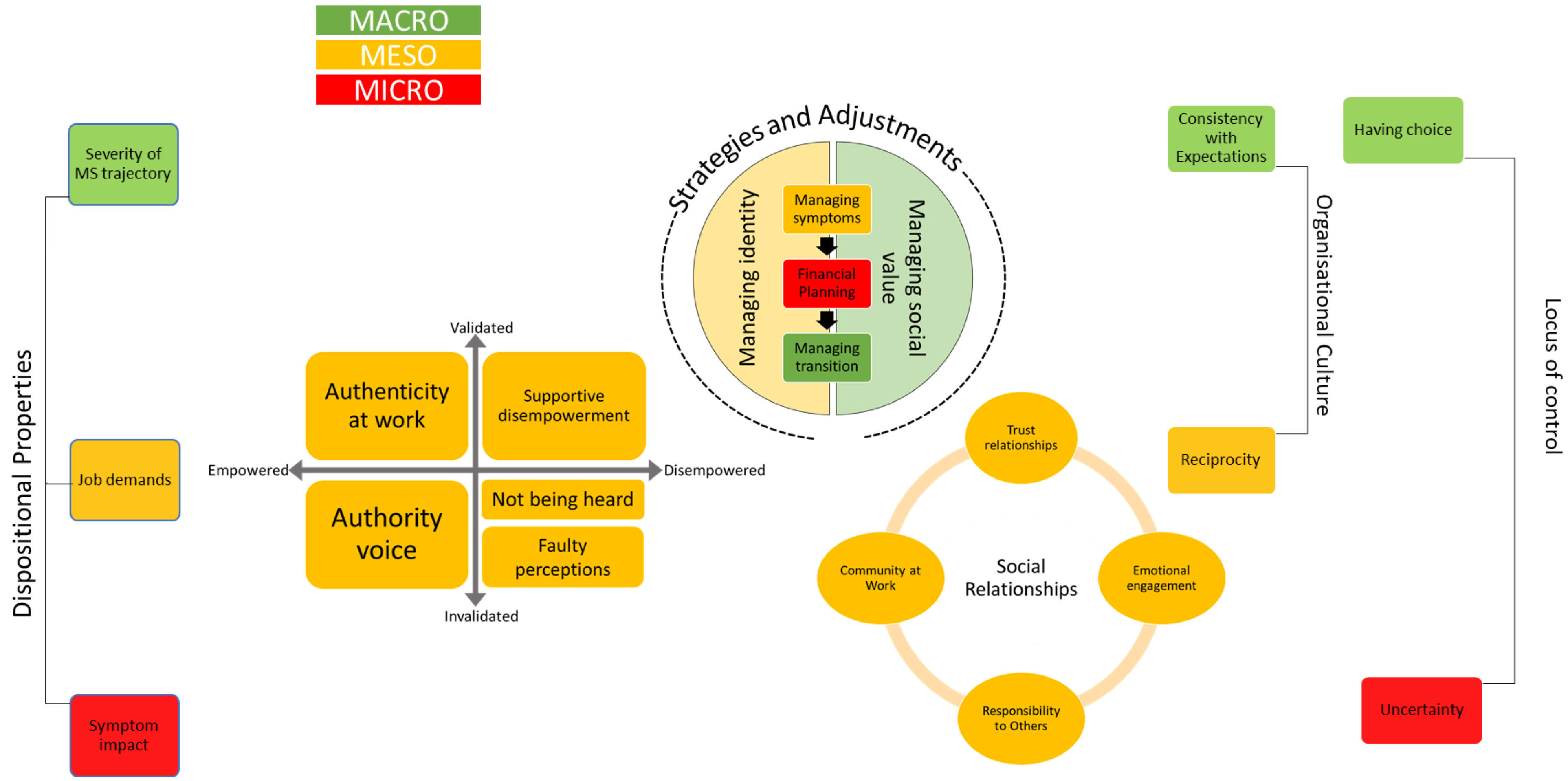

Figure 5.1 - Model of PwMS no longer in work

Theme 1: Dispositional Properties

Dispositional properties describe the characteristics of something that may result in a particular outcome, for example "fragility" of glass is the property that may cause glass to shatter. For PwMS who have left work, dispositional properties of MS and specific employment demands can be identified as factors contributing to cessation of work.

Theme 1: Dispositional Properties; Sub-theme: Impact of Symptoms

Impact of MS symptoms is logically a major contributing factor to how PwMS experience managing MS in the workplace. Higher symptom impact may mean an individual is more likely to consider leaving work, particularly if continuing work aggravates symptoms.

> *""It was no good for me really to be working, because I had no quality of life outside of work..." Niamh*

Although these symptoms may continue to impact individuals after stopping work, the magnitude of impact may lessen when the demands of work are removed. While MS can be such a variable condition, a common symptom is fatigue. Managing fatigue can be particularly challenging at work. Energy resources are more easily drained, such that activities such as commuting to work become additional barriers to continuing work.

> *"So there were physical challenges, and I guess fatigue, because quite often I would feel just kind of wiped out with fatigue, or lack of energy to do stuff. And also some challenges with transport, so my primary mode of transport, I live half an hour away driving from my workplace, so and there wasn't an easy public transport solution, so I drove in and out, so there's a little bit of car parking at work, quite often I'd have to park a long way from where I was actually due to be working, so there was a physical walking to get there." Neil*

In addition to fatigue as a direct symptom of MS, energy expenditures, such as physical effort can have a cumulative impact. For example, Nelly notes the exhausting impact of chronic pain as a symptom of MS. MS can generate physical symptoms, cognitive symptoms and psychological symptoms. Natalie notes how cognitive and physical symptoms impacted her ability to continue working:

> *"I'd had so many relapses I couldn't [...] I'd just, not forget what I was saying but the words just wouldn't come out or I'd start slurring or I'd totally forget my train of thought, so at that time I was in quite a bad place, I was walking with two crutches, I couldn't stand up unaided so I think whatever job I was doing, I think I might have just gone, no, I can't do this. And because I'd been so ill for that year I'd used my 6 months full pay, 6 months half pay, then you go onto no pay..." Natalie*

In addition to the stress of managing MS symptoms, the condition itself can have an impact on emotional response pathways.

> *"now whether it's me, I don't know, whether it's my emotions thinking how my daughter will be feeling now, because but I can just get very upset very easily like that. Other things like that, and then something on the television, you know, somebody says, oh well yeah, you know, an athlete, yes I did my best run today, I'm so excited, I'll do my personal best and I'll start crying,*

> *it's stupid, but and I think that's my MS as well, it's just playing havoc with my emotions. I don't know, it's difficult though because you've got to be careful you don't just go putting everything down to MS, you know?"* ***Nicola***

Theme 1: Dispositional Properties; Sub-theme: Job Demands

Although work is generally expected to have a level of demand, some work may include demands that are particularly incongruent with MS impact; MS symptoms can occur in physical or cognitive domains in varying severity, and different fields of work will require varying amounts of physical or cognitive demand. For Niamh, the specific type of work she was doing meant that adjustments did not seem feasible.

> *""…to be honest, it was really actually dangerous for me to be working there [laughs]" Niamh*

Naomi notes how the difficulties she faced at work were less to do with MS and more due to the lack of support she received in being able to fulfil her own role. Despite this, she was able to implement strategies to reduce the impact of this:

> *"So it, almost what I did, I think I taught better actually because I paired it down and made the kids more responsible. So that was all brilliant and I did all that but then I got a new head of department who I told virtually straightaway what my problems were and what my issues was, but really nice fella but no backbone and so he wouldn't discipline the kids. So I don't think that's anything to do with my MS, that was to do with I didn't get the support I needed." Naomi*

Practical demands, such as commuting can be a significant barrier for people with MS whose energy resources may be impacted by travelling to and from work. Neil notes that the physicality of walking back to his car after a long day of work was a struggle and could leave him unsteady in his gait. Nelly also notes that rush hour is less than conducive to managing MS and work:

> *"...I found after a few months that that wasn't viable for me, because I was, you know, getting in during rush hour and I was leaving at rush hour, you know, on the tube, it's, you know, you're basically rush hour and it's like sardines, you know, you're just standing forever. And you know, from work to home it's 17 stops, and with a change in-between, so I just, I couldn't do it…" Nelly*

Ultimately, the stress of work demands does not mix well with MS. As Natalie points out, MS feeds off stress:

> *"…because MS feeds off stress, your symptoms, you know, you are symptomatic if you are stressed, so that's another reason in the job that I did, you know, it's such a stressful job because it's other people's lives that you've got in your hands really." Natalie*

Thus, roles which carry higher levels of stress may be particularly challenging for people with MS trying to stay in work.

Theme 1: Dispositional Properties; Sub-theme: MS Trajectory

Much like symptom impact, disease trajectory can be a deciding factor in stopping work. For one participant, the rate of relapses meant that they were having to take extended periods of absence, to a point that medical retirement became the most feasible option.

> *"We counted up, I think I had 8 relapses in less than a year, which is more than some people have in their whole time that they have MS. And as [the consultant] said, the impact on me, because it took a lot of my memory, has been great so she fully supported me retiring on ill-health" Natalie*

Even where MS does not begin severely, the progression can reach a point that work feels infeasible.

> *"it is progressing rapidly, so I was having difficulty walking about before, I can't really walk about at all now, I can get around the house just, but if I'm going any, doing anything… and we've moved, we've moved house, because of my MS we've moved from the house we had into a bungalow, and it's only a small bungalow, so I can get around my bungalow. But even sometimes in here I'll sit on my rollator and I'll sort of wheel myself backwards because I can't walk around the bungalow itself, so I don't feel safe to be honest, I think even if I'd been on one level" Nicola*

For PwMS, who are diagnosed with relapsing-remitting MS, this can progress to become secondary progressive MS which may make staying in work too difficult.

> *"over time obviously my condition has deteriorated, and so initially I had relapsing remitting MS, I've now got secondary progressive MS, and I've had to make a number of other adjustments" Neil*

Theme 2: Adjustment Strategies

PwMS implement strategies to manage their MS and their employment. This theme comprises how PwMS who have left work implemented strategies during paid work, as well as the process of leaving work and adjusting to having left work. Strategies of *managing symptoms, financial planning* and *managing transition* are conducted within a broader context of *managing social value* and *managing identity* (Figure 5.2)

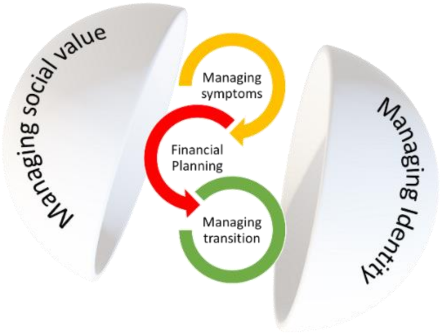

Figure 5.2 - Theme 2: Adjustment Strategies sub-model

Managing transition is a continuation of the *Adjustment process* (see Chapter 4); rather than M*anaging change*, which reflects strategies for implementing reasonable adjustments, the change being managed here is leaving work. *Managing transition* also includes continuing to learn about and adjust to the individualistic nature of MS.

Managing social value includes the aspects of social value that are discussed in Chapter 4. While PwMS in work might attain social value through work, PwMS leaving work must look beyond paid employment to find social value.

Theme 2: Adjustment Strategies; Sub-theme: Managing Symptoms and Fatigue

Symptom management strategies appeared to be successful when they were in keeping with the individual's self-identities. For example, Naomi utilised her methodological approach to work to make the best use of her energy resources:

> *"I've always been very sort of methodical about what I do but I almost had to be more methodical to keep a check […] because I wasn't really up to sort of like doing the running round at break time because I needed my break times, so I'd do sort of contact sheets which were actually flagged up as being an outstanding practice" Naomi*

In addition to these strategies being transferable for non-MS employees work well, they allowed Naomi to create a balance in her workload that kept her fatigue levels manageable.

As well as temporal strategies, physical adjustments can help with fatigue for PwMS. Neil found that having a mobility scooter reduced the energy used to move about his workplace, so that he could use that energy elsewhere in his work role. However, these adjustments can have limitations or cease to be effective:

> *"…so I'd do my kind of day, normal daytime work and I'd be completely wiped out in the evening, and weekends so I was finding I had no energy left for you know, other activities, and to do stuff at home. So it was having an impact on my home life as well. And I was, that I was still kind of struggling to get around the hospital site, so the work bought me a scooter to help me get up and down the long corridors, which was helpful but there was still places that I couldn't get into, because it was an old building some places are still, there's no way of accessing certain areas without going up steps, or some things, so you still have to walk around to get into" Neil*

As Neil states, fatigue and other symptoms may lead to individuals using all their energy at work and no longer having a good work-life balance. When the balance becomes skewed in this way, this seems to be the point at which PwMS consider leaving work. Developing strategies around fatigue are often necessary for PwMS. As Nelly points out though, this can become an all-consuming task that prevents individuals from being able to engage in their work or other aspects of life:

> *"… because with the fatigue I can't always concentrate, and when it gets that bad, when you've got pain going on as well it's massively distracting, and you just can't focus on what you're doing, so when you're standing supposedly for an hour and a half's workshop, yet you have to try and strategize […] I think MS is strategized every day, whether they're at work or not, so we're kind of quite gurus at it, but I think when you're over strategizing and it's literally becoming all you can think about every single day like when you eat versus when you're going to have that workshop, you know, it's crazy." Nelly*

Natalie also notes how contributing all energy resources to work to a point that you spend all time outside of work recovering, this is not a suitable way to live.

Nicola states the importance of not attributing everything to MS. This forms part of the adjustment to MS in learning how it affects the self and determining what is and is not due to MS. It is important not to conflate MS to all symptoms.

Theme 2: Adjustment Strategies; Sub-theme: Financial Planning

Leaving work seems to be the result of a cost-benefit analysis. If the benefits of leaving work are high enough in comparison to the costs of staying in work, this may be the point that PwMS decide to discontinue with work.

> *"Well the big push was the fact that when I work out my pension I'd be paid half what I was earning working full-time to not work at all." Naomi*

The benefits of leaving may not be directly higher than staying; as Naomi states here, she will receive half the amount of pay. However, this combined with the removal of costs of working, such as stress, makes the decision to leave work preferable.

PwMS have to weigh up their options when it comes to leaving or staying in work. For Natalie, retirement became the only sustainable option due to the severity of her condition meaning that her paid sick leave had been expended.

> *"…[Husband]'s got his own business but when he works, you know, it's feast or famine and he's winding down a bit so I knew my money was coming in every month and we lived to our means, so all I could see was well if I don't take my retirement we are going to be left with no money, because we've got money we can't claim any benefits or anything, so I've gone from 3 grand to nothing, so I had to make a decision and to go down the route of medical retirement with the NHS, it isn't like oh okay then, it's a long process and even then I had to fight for... They're called tiers…" Natalie*

The role of family, particularly spouses who may or may not be providing their own income to the household is clearly relevant to these decisions in when and whether to leave work.

Participants discussed the adjustment to a lower income due to leaving work, and how this could be challenging. Different participants had made previous decisions which related to their financial situation and helped reduce some of this pressure. Nelly had accumulated savings, which made her situation viable. Neil had previously taken on extra work roles to boost his income in previous years and Nicola had taken out health insurance prior to her MS diagnosis. For Niamh, leaving work simply was not an option until she had paid her mortgage in full.

> *"… a lot of it was financial. Because I wasn't actually prepared to give up work unless I was like secure. And, erm, and for me that just meant I had…I wasn't prepared to give up work unless I paid my mortgage off which luckily I managed to get it paid off. And then, erm, I was also really worried about being able to get any benefits. So, while I still had a mortgage, I wouldn't think about giving up work…" Niamh*

Financial pressures extended to responsibility for others in the household. For Neil this was still having dependent children. For other participants, they had been the source of a consistent income while their partners were working in roles such skilled trades, which can see peaks and troughs throughout the year.

Theme 2: Adjustment Strategies; Sub-theme: Managing Social Value

Work provides a form of active engagement and gives individuals a sense of purpose. Neil found his type of work rewarding and found positivity in ensuring he shifted his focus to other meaningful activities outside of work, such as spending time with family.

> *"And also you know, you know, obviously with work you have a sense of, it's quite a rewarding kind of work, so that's not there anymore. So but I'm also glad because I've got more time for my family, and more physical resources to be able to, you know, or I've less fatigue, so I'm able to do more out of work than I was able to do before" Neil*

Nicola also felt it was important to continue with meaningful activities outside of working.

> *"So and that still gives you a sense of you're doing something, you know, you're not just sat at home watching Jeremy Kyle on the television" Nicola*

Natalie also made reference to avoiding daytime television, which is conceptualised as wasteful and a meaningless way to spend time. Nelly goes further to describe the benefits of continuing meaningful activities, as a way to keep cognitive faculties engaged.

> *"…but particularly now I'm always thinking about what's the next thing I could be doing, you know, and just so that I'm not always sitting on my laurels, because to me that's the worst thing I could do for my MS, so if I can try and, you know, improve myself, and keep my cognitive faculties as good as they are, then that all the better basically. So I think that's what I mean, those little things like going out every other day and meeting with people, you know, being quite active on social media, you know, those sorts of things are really, really important to me." Nelly*

Participants were consistent in their opinions that continuing to be actively engaged is important.

Theme 2: Adjustment Strategies; Sub-theme: Managing Transition

Leaving work is a major life change which requires adjustment. Managing this transition plays a major role for this subgroup. Not only are participants managing the transition of leaving paid work, but this is also often coinciding with deterioration in their condition. Thus, coping strategies are important for how wellbeing is maintained at this crucial time.

Participants discussed the psychological impact of ceasing paid work.

> *"in some ways quite difficult again mentally finishing work because you feel like well you're not, I'm not doing anything specific anymore, or I'm not contributing work wise, because work has been quite a big part of my life, so that's a difficult change." Neil*

For some this process is much more difficult. Natalie finds that adjusting to the diagnosis and leaving work are both presenting psychological distress. Where MS is severe, it may be difficult to adjust or find meaningful activities after work. For her, MS has followed a severe trajectory, meaning that her diagnosis and retirement were in relatively quick succession. The opportunity to process these changes mentally has been limited and presented a challenge.

> *"I think I'm still trying to come to terms with the fact that a) the diagnosis and b) that I've had to give up, even though I sort of moaned about how stressful it was because it was my*

> *life and I think, people say well retire but like ooh, you know, make sure you've got plenty to do because it's a massive shock, well I can't have plenty to do because it tires me out so much so."* Natalie

Nicola details her strategies for adjusting to the on-going fluctuations and progression of MS.

> *"And you literally do just have to think, right, well, I'll see what's happening tomorrow morning, and each morning you wake up and you realise you can still walk and you can still talk, and you can still see and everything's fine, you think, great, it's a good day today. And I always said my 100% was different to everybody else's 100%, my 100% was if... I mean for example one of the first major things that started to happen to me was I had, I was having bladder problems, so that took my 100% down if you say to say 90%, but as long as that stayed at… as long as my body didn't get any worse, that 90% now became my new 100%..."* Nicola

Theme 2: Adjustment Strategies; Sub-theme: Managing identity

The impact of MS on self-identity is important, and the changes to working it brings can have a significant impact on individuals. Naomi copes with these changes by focusing on what aspects of her ideal self she can maintain:

> *"…it's like for me it's really important to find out what I can still do and what I can do I need to do it well."* Naomi

Nelly utilises aspects of her previous self to create solutions for her future. This allows her to maintain her identity going forward.

> *"I'm quite a creative sort of person and I like to find creative solutions, and this seemed to be a really good one, so yeah, I hope it works out…"* Nelly

For Natalie, she realised the aspects of her previous self that she was unable to continue, and describes this loss:

> *"I actually applied for a job because I got where I felt quite well and I was getting quite bored at home because I've always been, you know, I've always been a doer and that so I applied for a Band 4 […] and because I've worked as a Band 8A […] I was preparing for this interview and I was so stressed and me fizzy feet and I was so fatigued and tired and that was just me getting me head round but I think I was preparing for something, you know, I thought I'd have to go and do a presentation or something and really, it's a Band 4 but I was, because I don't think at that level […] All me symptoms were coming back, me speech was worse and I think it was because I was concentrating my efforts into... Because obviously you know about MS don't you, because everything's got to work differently, that's really hard work just to function so when you add anything else into the mix it's like... It's like ooh, so you just can't and I was just so fatigued and that made me realise and I cried. […] It's like a bereavement really."* Natalie

The bereavement of the former self is a process people with MS ay experience following diagnosis and again after leaving work.

Theme 3: Dis/Empowerment In/Validation Matrix

People with MS in the workplace find themselves somewhere on a matrix of empowerment and validation (Figure 5.3). The 'gold standard' is *Authenticity at Work*, where the individual is both validated and empowered regarding their MS. However, PwMS may find themselves validated but disempowered by misguided actions of their employer. Alternatively, PwMS might utilize the authority voice of a HCP, which essentially empowers them while continuing to invalidate their own voices. Further, individuals who feel they are not being heard, as well as those subject to faulty perceptions of others experience both invalidation and disempowerment. PwMS who have left work are able to reflect on their experiences of validation and empowerment from a distance, in contrast to PwMS in work who are still entrenched within the validation process as described in Chapter 4.

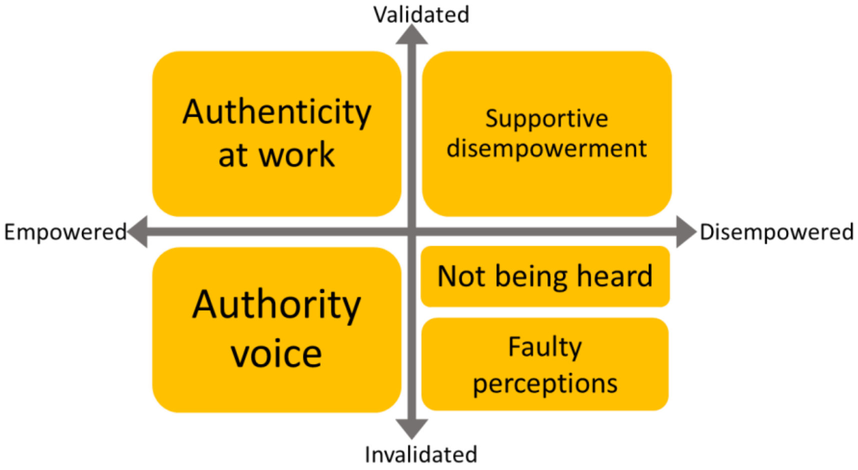

Figure 5.3 - Theme 3: Dis/Empowerment In/Validation Matrix sub-model

Theme 3: Dis/Empowerment In/Validation Matrix; Sub-theme: Faulty Perceptions (Disempowered, Invalidated)

A major challenge PwMS discuss is the misconceptions, or false assumptions about MS. It seems common that people who have known an individual with MS previously assign the same knowledge to all PwMS, which can be frustrating and invalidating.

> *"And there's always somebody that knows somebody that's got MS, they're absolutely perfect and they've had it for, ooh they've had it since they were 20 and you wouldn't know and oh and they work and they've got 20 kids and they're amazing and they run marathons and the GP was very much like that, he was very like, you know, get a grip, you know, he was." Natalie*

Naomi had a similar experience at an MS information day about someone with MS who could still ride a horse. Although intended to be encouraging, these comparisons can feel invalidating for PwMS who are not experiencing the same low levels of impact. On the contrary, hasty generalisations often include the stereotype of PwMS as wheelchair users, despite many not being so:

> *"I got the real idea that she thought I was sort of making it up, you know, and it was like, and I did actually say to her "do you know anything about MS?" and then she started telling me about a very good friend of hers that had MS so she did understand about it, and this poor lady, even though she was very good, was now in a wheelchair [...] And then I should be a role model because there would be other people at school who would be in a wheelchair. I'm not in a wheelchair." Naomi*

Nelly also mentioned the wheelchair stereotype.

There can be social shame associated with the symptoms of MS due to lack of knowledge or awareness.

> *"So I'd get people asking me if I was alright, and you know, occasionally, because if you're very wobbly legged it can look like you're a bit inebriated when you're perfectly sober, so it's just a bit embarrassing." Neil*

A common misconception is that the individual is drunk. Nelly also mentioned this, in relation to slurring speech, when fatigued. Without the context of understanding MS, people may make false assumptions that have negative social impact.

Neil also relates to this reluctance of discussing personal details with colleagues, who raise questions at work but may not know about MS.

Nicola ascribes lack of understanding to the invisibility of MS. Although her employers offered significant adjustments (to a point that felt disproportionate and disempowering to her), simultaneously, colleagues lacked comprehension of her less visible symptoms which did not fit to their perception of her overall.

When people are unable to comprehend MS symptoms, or question them, this can be hugely invalidating for the individual experienced the symptoms.

> *"I got a letter back saying, thank you for everything that's been submitted, however, we do need more information because we understand that this is a treatable condition and you will record on this, so we need to understand why you feel that you can no longer work." Natalie*

Theme 3: Dis/Empowerment In/Validation Matrix; Sub-theme: Not Being Heard (Disempowered, Invalidated)

Feeling listened to and understood is empowering. When PwMS feel heard, they have more positive experiences in work, and in leaving work.

For Naomi, despite providing information for her employer, she did not feel her MS was understood or adequately acknowledged. Although some adjustments were made, these were not necessarily enforced or upheld. When see sought further support, the assumption was that she was trying to get out of work rather than continue:

> *"her first comment was "so why do you think you can't work?" That was a complete, that was the first thing she said to me and I said "no, I'm here because I want to work, I'm here because my management have asked me to come and talk to you and I'm not trying to get out of working, I want to work, I just want to try and, if you can help with any adaptations and to fit the Health and Safety at Work Act". So I just came away feeling really sort of demoralised" Naomi*

Neil had mostly positive experiences with his employer taking his MS seriously, with relevant processes in place to ensure he was supported at work. However, he described some negative events with some managers and colleagues who were less understanding of his MS.

> *"for a, a particular phase when there was this particular manager, so that some things also happened were I requested some adjustments because of I was having physical difficulty doing some of that, there was adjustments never happened, so I had to keep, carry on doing what I was doing, so you know, obviously that's quite challenging, physically and kind of mentally, and as well, because it was, you know, I guess kind of difficult to cope with having a physical, having and feeling like I had to do the same things and I wasn't quite able to, I wasn't quite up to them physically." Neil*

The impact of this response is demoralising and invalidating for people with MS, who are seeking equal opportunities at work.

Some barriers that people with MS face are due to a lack of awareness on the part of able-bodied people. Nicola discussed multiple experiences where able-bodied design had not taken into account accessibility issues. Even where 'accessible' ramps had been added, a doorway threshold meant that a wheelchair still could not enter a building. Kerbs that may appear only slightly raised to an able-bodied person are significant mobility barriers to those with reduced mobility.

Nicola had multiple experiences of colleagues not comprehending how MS impacted her. Some of this was tied to invisibility of symptoms; despite her explaining some things, colleagues did not seem to take on board invisible symptoms as it has in contrast with their perception of her. For example, they see that she is intelligent therefore cannot comprehend her cognitive symptoms. Although Nicola's colleagues understand her to be an intelligent person, this is conflated with cognitive symptoms from her MS which affect her memory.

> *"I don't think people understand that that side of it, I don't think people… people can see that you can't walk very well, people can see that your hands aren't working very well, anything that's visible is fine, if you turn around to somebody and say, "I've forgotten, I've forgotten," they're going to say, "Oh for heaven's sake, come on, why are you forgetting, I told you last week," they don't realise that MS affects your memory like that as well, and as much as you say to them, "It's my MS," I think people kind of think, oh she's pulling that one again, it's her MS." Nicola*

However, some aspects of MS are difficult or uncomfortable to talk about, particularly with people who maybe are not as close socially.

Theme 3: Dis/Empowerment In/Validation Matrix; Sub-theme: Supportive Disempowerment (Disempowered, Validated)

Although responses from employers can be well-intentioned, it can occur that adjustments implemented are disempowering or unhelpful. This seems to come as a result of not having understood the needs of the individual or creating assumptions about what course of action to pursue.

> *"…And one of his suggestions was that he'd get me a harness to sit in, a body harness." Naomi*

For Naomi, in addition to the proposed adjustments feeling vastly disproportionate and disempowering, she saw that she had been shafted with the less desirable work in response to her MS:

> *"But you see it's almost like giving the person that can't do the shit job really […] I mean obviously somebody has to do it but they could have just put me on there for an hour couldn't they…?" Naomi*

Naomi describes other adjustments that were not suitable or created further barriers to her during her working day. These were a result of others thinking of solutions through an able-bodied lens. Nicola describes this concept in various experiences of able-bodied design in the wider world. As an example, she explains the difference in accessibility of vehicle access kerbs versus wheelchair access kerbs. Although someone who navigates crossing the road by walking may not notice the difference between these, a wheelchair user certainly does when they become stuck in the road.

For Nicola disproportionate responses from her employer were well-intentioned but overly paternalistic, to a point she became disempowered in her sense of self-efficacy:

> *"No, but then after this fall and they were saying, "No, you don't go downstairs and you don't go upstairs into the top filing space," and I thought, well that's not what you employed me for, you employed me to do that and now I'm having to put 50% of my workload and having to put onto my office mates, and she's got her own work to do, she doesn't need to do mine as well"" Nicola*

Where employers are attempting to be supportive, this can take away opportunities for employees with MS, who may otherwise feel capable of meeting these:

> *"I think they give me support, and have given me support, I think sometimes I've had to challenge that support a little bit because it's either been a little bit OTT, or [laughs] it's been in a way that I didn't plan on it being, so you know, I've had to sort of reign them in a little bit and kind of, say, "No, no, I didn't quite mean it like that, can you just please to give me opportunities, I don't want to completely like do myself out of these opportunities," so things like that…" Nelly*

Theme 3: Dis/Empowerment In/Validation Matrix; Sub-theme: Authority voice (Empowered, Invalidated)

A final point in the dis/empowerment in/validation matrix is the use of the authority voice. PwMS who are experiencing invalidation may utilize the authority voice of a HCP. Despite continuing to invalidate the individual, there is an empowerment provided through the voice of the HCP which helps individuals to access support at work.

> *"… at this point I got in touch with my physio and I said, "please can you just write me a note and say whatever, however bad my position is, if I'm just given enough space I'll be able to get downstairs, you don't really need to have me stood at the corner of a staircase waiting for the exit strategy for the fire procedure". So they sort of accepted that..." Naomi*

Even for Nelly, who described her employers as generally supportive, the additional ‘clout’ of the HCP enabled her to access support in a timelier manner:

> *“I just thought, right, I’m just going to pull rank a little bit here, and I went to my MS nurse and said, “Please can you help me, I’m so desperate now,” and she wrote me a letter really quickly, scanned it to me, I printed it off and I literally handed it to my manager, and I said, “I need this now, this is what I need,” and after that it went really, really quickly. So I think that extra level of clout is what people sometimes need, behind them, I think, yeah.“ Nelly*

Theme 3: Dis/Empowerment In/Validation Matrix; Sub-theme: Authenticity at Work (Validated, Empowered)

Authenticity at work could be considered the gold standard in terms of empowerment and validation. This relies on a workplace that is psychologically safe, supportive in its culture and is open to learning and diversity. An approach to learning from others and empowering individuals is more useful than direct knowledge of MS.

> *“…if I feel like I can behave authentically then I’m just literally just giving 100% of myself. So it’s important to me as a performer, a good performer to feel like I’m supported, but if I’m always feeling like I’m being questioned, or doubted, or whatever then it doesn’t work.” Nelly*

Nelly had positive experiences with her recent employer, in that they were very understanding if her needs differed in some way. If she needed to make an adjustment, they were accepting of this, even as simple as changing a video conference to a short phone-call. These small adjustments are unlikely to impact others in any negative way and allowed Nelly to continue to work without additional challenges. Nicola also discusses the importance of authenticity in keeping barriers to a minimum:

> *“I feel if you don’t tell them that you’ve got MS it can be such a debilitating disease, whether that’s for a day, a week or however long, you’re not actually telling them who you are, you know, you’re hiding part of yourself, and they want to employ you because of who you are, not because of who you’re pretending to be, and I see it really well, you know, it’s a big part of... it doesn’t make you the person, and I’d always said MS doesn’t have me, I have MS.” Nicola*

For Natalie, despite her employer being aware of her MS and implementing shallow support strategies, being able to authentically express herself was a challenge. She felt invalidated in herself due to the disparity of her MS experiences compared with a friend.

> *“I’ve got a friend who has just ran a marathon and he’s got MS but he hadn’t got a formal diagnosis of MS, so it was an awful time because I was sort of thinking, I’ve got to pull myself together and try and crack on with feeling right and clearly, you know, I wasn’t and I was struggling. But work? Yeah, once I went back to work I was supposed to meet with this higher manager weekly to see how I was doing and she’d always ring and go, I’m so busy but you’re alright aren’t you? And I’d go, yeah, of course I am but really actually...” Natalie*

Theme 4: Social Relationships

Theme 4: Social Relationships; Sub-theme: Community in the workplace

Participants sometimes appeared surprised to realise that work had provided a social community, which they may feel they have lost after stopping work.

Although Naomi did not feel her colleagues equated to fully fledged friends, she did consider that she had lost a social side to her life after leaving work. Work makes up a significant portion of social interactions for working-age adults.

> *"Because you're almost a bit removed from the really close relationships and almost the MS stopped me from developing those close relationships because I didn't, I stopped going into the staffroom because I didn't have the time or always the energy to almost waste to go and sit down. And I did always make sure I stopped for a break but sometimes I was thinking "oh gosh, if I've got to walk to the staffroom to sit down"." Naomi*

For Naomi, her MS presented a barrier to developing social connections with her colleagues. This experience was not unique to workday breaks, but also staff social events outside of work. She spoke of occasions where she had needed to take time to rest after her workday and by the time she was recovered, her colleagues were finished socialising. This causes speculation for whether this is a lack of consideration on her colleagues' part, or due to the social relationships not existing enough yet for her to be able to raise it.

> *"…loss of companionship because I don't see my friends and colleagues at work anymore, or rarely. So kind of loss of that community that I had before, because that's, you know, inevitably not going to continue." Neil*

Neil discusses the gap that is left when leaving work, through loss of the community that is experienced through work. Nelly also feels this and has developed strategies outside of work to maintain a sense of social connection.

> *"So yeah, I guess and that connection is important, so interestingly I started substituting the face-to-face stuff with online communities, that didn't make… it feels so bad after a while, and now when I, I make sure that I get out at least every other day to sort of be within people, so I'll go to a café and I'll just, even if it's to take my laptop, I'm not even meeting anybody, I'm just being with people and that seems to have calmed that side of me down a little bit." Nelly*

She notes that work is one of the biggest readily established frameworks of social connection. In addition to losing connections when leaving work, Nicola alludes to the risk of social isolation that may come with being out of work. Although her partner has a working pattern that does not leave her alone too long, others may see themselves at home for long periods while their families are out at work or school.

Theme 4: Social Relationships; Sub-theme: Trust relationships

For those who disclosed their MS at work, this seemed more related to telling a person they trust, or a close friend rather than telling colleagues or even employers. Holding a trust relationship with someone at work seemed to be beneficial to managing aspects of MS, practically and emotionally. The support of colleagues as friends was important for PwMS during more difficult periods of their MS:

> *"... they did come to see me at home as sort of friends really." Natalie*

Participants discussed disclosure decisions in relation to trust relationships.

> *"I told some work colleagues, so I told my closest work colleagues, partially because they were also friends, and partially because I worked with them so closely I just, you know, I just wanted to let them know." Neil*

Naomi also considers that she confided in friends but did not want to disclose to many people in the workplace. Naomi also notes how telling friends can elicit the right sort of support that she found she was less able to access at work. However, disclosing at work if those strong trust relationships aren't in place is difficult to do.

> *"...you've really got to almost share a lot of who you are and what you are to get the help from people that you don't necessarily know that well." Naomi*

Nelly shares that disclosing and building trust are interrelated; she felt that disclosure should happen once a relationship has foundations, but also disclosing can be a means to build trust.

> *"...when I have disclosed it's normally been at the point of either the offer or when I've been in the workplace for a few weeks and they've seen what I can do, they've seen my attitude, you know, they've seen I'm a good performer, so that they have some emotional investment, so when I actually tell them they know that it's because, you know, I'm having to tell them and it's because it's kind of, it's there to build trust rather than to remove it." Nelly*

As Naomi noted, Nelly says that disclosing requires opening up. However, she points out that disclosure is not a single event. As she describes it: *"...you have to constantly open up ...".*

Theme 4: Social Relationships; Sub-theme: Emotional engagement

Participants noted that others responded to their diagnosis disclosure could be notably dichotomous, as either avoidance or over-engagement.

> *"I found some colleagues just didn't want to engage, engage with me or became a bit more weary of me I would say, or that maybe because they didn't want, they wanted to avoid talking about the topic of MS and you know, I guess it's quite personal talking about the affect it has on your health and life. So I would say it made a few people a bit more distant, and yeah, a few people completely the opposite and much more engaged." Neil*

This could be related to how well others handle difficult situations.

> *"I am really quite scarred by having cancer because, metaphorically and literally, but lots of people aren't emotionally equipped to deal with bad things. Because I had people I thought were really good friends that sort of like couldn't cope, it was too upsetting with me having cancer. [...] And I think now it's almost like MS, oh that's really upsetting too." Naomi*

Nelly felt these disparate responses are part of the human condition.

> *"...I think it's part of the human condition that you will get some kind of reaction, so either people will find themselves feeling instantly sorry for you, or they'll find themselves kind of*

> *thinking, oh crap [both laugh], you know, what does this mean for me and my team and what am I going to have to go through" Nelly*

Nelly noted also how management training around employees with disabilities was focused heavily on fear of litigation and less on disclosure conversations, which may be more useful.

Theme 4: Social Relationships; Sub-theme: Responsibility to Others

There seemed to be a sense of responsibility related to working, possibly related to maintaining social value. This was discussed in terms of it being moral and honest to disclose to employers, in case MS deteriorated. This sense of responsibility to the employer to allow them to plan ahead could be linked to the concept of being a good worker. A sense of responsibility to co-workers was also portrayed, with participants mentioning that they felt guilty or were letting others down in some way. Finally, this accountability was also discussed in terms of willingness from both sides to make adjustments in order to manage challenges.

> *"I felt it was better to be upfront about it, than you know, keep it quiet, because I thought I was just… well partially I felt it was a more responsible course of action, and also kind of to protect myself, you know, if there were, you know, you know, if problems arose at work" Neil*

Nicola also felt that disclosing MS was the responsible course of action and felt a sense of responsibility toward her employer. She discusses how honesty is better than the risk of having a flare up and having to tell more lies; disclosing is about being honest. Despite disclosing at the time of applying for her previous job, she continued to feel guilty that her MS had progressed, and she was no longer able to do the work her employer had hired her to do.

> *"… I felt awful, you know, I thought, I couldn't do the actual job that they'd employed me to do in the end because I knew to not go upstairs or downstairs, but on the same hand I felt guilty that they'd employed me knowing that I had MS, but when they had employed I was okay…" Nicola*

Further to feeling guilty about the impact of her MS, Nicola also had experienced anxiety of asking for help. This may be indicative of wider social norms in regard to help seeking.

> *"But then hearing how they'd had to suck up all this, that was quite stressful hearing about, you know, because I felt I was letting people down and like my colleague […] they didn't put another manager in or anything, she was just... You know, she left in the end because it was all too much…". – Natalie*

Theme 5: Organisational culture

Organisational culture creates a framework for the interpersonal interactions people have in the workplace as well as setting cultural norms of behaviour and expectations. Participants talked about the need for a 'willingness on both sides' which is covered in *Reciprocity*. On a wider contextual scale, *Consistency with expectations* is synonymous with societal norms and personal expectations around work and retirement.

Theme 5: Organisational Culture; Sub-theme: Reciprocity

Reciprocity in the workplace is the feeling that the effort you give to work is reciprocated in some way, through cultural approaches, e.g., attitudes such as gratitude, feeling appreciated at work or feeling valued. Those who felt that their work environment was one in which courtesies and deeds would be returned had better experiences. Some of this fed into the concept of being a good worker.

> *"And then they decided that that wasn't part of their job to lift and carry things. And even though I sort of had a word, because then you get into sort of silly stuff, you're like "the caretakers won't lift the heavy bags out of the car", "oh well no, health and safety lifting and stuff", like "well hold on how am I supposed to do it then?" So then the head technician he said "oh you're", I didn't tell him what was going on, just a nice guy, he said "you're struggling carrying these bags in, if you just give me a shout I'll come and get them for you". So he did." Naomi*

This experience at Naomi's workplace highlights that despite different approaches of colleagues within the same organisation, the overall culture did not appear naturally supportive. Nicola also discussed how poor implementation of general policies at her work and colleagues not fulfilling their own duties often left her under increased strain, irrespective of any impact of MS. Natalie also felt that her efforts were not fully reciprocated by her organisation:

> *"…so if you are sort of flogging yourself and somebody comes and says, you have to remember you are just a number, you are replaceable…" Natalie*

Nelly felt that her employers were more receptive of her needs due to her initiating an attitude of willingness. She described that her approach to requesting adjustments focused on the benefits of both parties:

> *"…I think if you try and sell it like some sort of business case it's massively impactful on the person you're asking it from. So it's if you can tie it in, so for example when I went part-time from going full-time I did it with the knowledge that they were trying to save 10% of the department's budget […] I sort of said, "Look, I can do three days and you'll be saving X amount of money of my salary," you know, and things like that. So I didn't have to do that, obviously by law you're entitled to ask for things, but and it wasn't like I was asking for a huge amount anyway but it just made my case stronger I think." Nelly*

Nelly also noted the importance of having a good relationship with your manager, as their perception of you could be hugely influential on workplace experiences and access to adjustments. Neil also noted that your employer's perception of you is important to how well you are able to access adjustments:

> *"…if you're perceived as being a, you know, a hard worker, not a troublemaker, someone who gets on with it, someone who's helpful, and keeps their nose clean, it stands you in very good stead. So I think if you are well regarded in your workplace then that's a definite advantage when more troubling times come." Neil*

Theme 5: Organisational Culture; Sub-theme: Consistency of Expectations

Individuals may hold expectations or expected norms of work. For example, being closer to what was considered a normal retirement age or being near the age someone had planned to retire seemed to make the adjustment of stopping work easier. This also applies to reasonable adjustments; where the adaptation is less costly or complicated than expected, this can feel like a 'win' to employer and employee.

Nelly discussed how adjustments do not need to be costly or complex; for example, a desk fan had made a significant improvement to her ability to continue working through symptoms related to temperature regulation. Contrarily, she felt her employer had exceeded expectations in their approach to making changes for her to stay in work:

> *"…we went into a building where we were supposed to be on a different floor but because I couldn't get up those stairs very easily they moved the floor, but they didn't just move me, they moved the entire team [laughs], so which must have come at costs, so you know, there are lots of different approaches people have, but you find there are, that sort of the written policies and any informal policies as well, and that people are more willing to do things locally and off label if you like, than always follow sort of the policies if it means getting the job done, if that makes sense?" Nelly*

For Nicola, her expectations of work norms were not consistent with how her organisation operated, which was a source of anxiety for her.

> *"I started work at nine, but I couldn't turn up at nine o'clock, it's just not in my programming, so I was always there at like 20 to nine, and [laughs] on the front of the building, because it was a terraced house, they had metal shutters that you had to unlock at the bottom and push up, and again I couldn't do that, so although I'd be at work for 20 to nine, I would be sat in the car waiting for somebody to come at nine o'clock to open the shutters up to allow me in. But I still couldn't get there any later than 20 to nine, if I was any later than 20 to nine I felt that physically if you like I felt as though I was late for work" Nicola*

Neil managed to work beyond his expectations, which may have been positive in his adjustment to leaving work. Being able to fulfil an expected life trajectory likely has a positive psychological effect.

> *", I thought I would probably have to finish work a lot sooner than actually, so I'm 54 now, so but you know, looking back I thought, yeah, a number of years before I thought oh I'll be lucky if I get to 50, so yeah, and in a way I was quite pleased that I managed to push on for a bit longer" Neil*

For Naomi, her retirement also coincided with an age she had expected to be leaving work. Further to this, she had remained in work following illness to prove to herself that she could and met her own expectations. Natalie also had expected to retire around the age that she did. However, her retirement process didn't feel consistent with her full expectations.

> *"I always said I would retire at 55 and do something completely random but if that's your choice that's fine but what's happened to me is not my choice. And when you're young and you think, 55's a long way away, I'm definitely not working after 55, it's different when you actually get to that age because you still feel 18 in your head. Or I do anyway, maybe 19!" Natalie*

Theme 6: Locus of control

Theme 6: Locus of Control; Sub-theme: Uncertainty of MS

MS is an unpredictable disease. However, for Naomi she felt that this had led to a heavy focus on negative outlooks:

> *"MS is a very unpredictable disease. Unpredictable, and you think "oh God". Because all the information I got was it was really degenerative. Nobody told me that you could almost plateau and stay there." Naomi*

Neil notes the uncertainty of how MS will progress, and the mental impact of that. Having known a family member with MS who had been severely impaired, he could not be sure if he would deteriorate as severely. Neil considers that strategies to cope mentally would have been beneficial.

For Natalie, her previous knowledge of MS had generated a fear of the condition for her. Living with fear of uncertainty or unknown is understandably detrimental to psychological wellbeing.

> *"…all I could see was these MS patients that as a young district nurse, district nursing sister back in the 90s because in those days you might get a bit of beta interferon but a lot of people weren't treat that was, you know, they got catheters, they were hoisted everywhere and that is and I've still got that, I've still got that picture of this is MS and that one day, you know, that may be me sort of totally dependent on other people and it's quite scary." Natalie*

Natalie also discusses the difficulty of planning too far ahead into the future, due to uncertainty. On the other hand, Niamh sees the lack of control over MS as a reason not to fret over it.

> *"I can't change it. I've got MS, I can't…there's nothing I can do really to stop it. It's how it is, so the best thing is just to get on…" Niamh*

Nelly also talks about the uncertainty of MS; the trajectory is unpredictable. The uncertainty can be frustrating, particularly at the time of diagnosis.

> *"…that was so hard because I felt nobody could answer any questions for me, and I kept thinking… I'm not asking the questions in the right way, they're not understanding what I'm wanting to know because nobody could give me an answer, and it was only sort of as I got more used to the disease and how it is for everybody and how it's so different for everybody, that it wasn't actually me asking the wrong question, it was nobody could actually give me an answer…" Nicola*

Theme 6: Locus of Control; Sub-theme: Choice and Control

Participants had varying experiences of how much control or choice they felt they had in terms of leaving work. Where participants felt this was something that they had better control over, the experiences seemed to be more positive.

For Naomi, she felt the decision was hers and she was supported by her family in choosing to retire. She also feels a greater sense of control in her activities now that she has left work, including voluntary work which she can cancel if she is not feeling up to doing.

> *"So I've no control about the MS but I can control what's going on in this body besides the MS. Does that make sense? Yeah. Because I can make myself as fit as I can be, as healthy as I can be and do as much as I can…" Naomi*

Nelly describes the impact of MS leaving her with no choice or autonomy. This is similar to others who experience severe impact of MS.

> *"but there is nothing you can say to them to do because you literally haven't got any other options, you just, you know, I just said, "Look, I have to put my hand up here and say I'm in too much pain to work here, I cannot" Nelly*

For Neil, when making a decision to retire on ill-health, the support of his employer and peers was helpful.

> *"…so I instigated that with my occupational health team, and then there was a whole process to do, […] it's quite a long process to go through, but that the people I dealt with were supportive of my application which was very helpful." Neil*

Neil's experience was relatively positive as a result of feeling supported in his decision to take ill-health retirement. This support gave him confidence in his actions, and validation which lessened the uncertainty that he would be successful in his application. On the other hand, Natalie spoke of feeling reliant and not in control with her application; although she too was successful, she did not have the same confidence throughout her application process.

Discussion

This study seeks to understand the facilitators and barriers to job retention for PwMS as well as the broader contextual factors that influence these. This subset of PwMS no longer in paid work explores in depth the experiences preceding and postdating leaving paid work with MS.

The objective for this subset was to interview 6-8 PwMS who have left paid employment no more than 12 months prior to interview and who cover a range of occupational settings, such as sector type and organisational size. Six key themes were identified via critical grounded theory analysis; *Dispositional properties, Adjustment strategies, Dis/empowerment in/validation matrix, Social relationships, Organisational culture*, and *Locus of control.* These themes consider social and contextual factors that influence employment and retirement outcomes, as well as interpersonal processes and individual level factors. The themes are discussed further with respect to the extant literature and theory.

Theme 1: Dispositional Properties

Reflecting on their experiences of work and factors that influenced their leaving work, participants noted dispositional properties such as *Symptom impact*, J*ob demands* and *MS trajectory*. Although descriptive in nature, these themes highlight important aspects of experiences related to staying in and leaving work for PwMS.

Participants had varying degrees of impact from their symptoms, although all participants were able to recount how their individual symptoms had impacted their experiences of being in paid work. MS symptom impact is well-documented regarding work-related outcomes (O'Connor, Cano, Ramio i Torrenta, Thompson, & Playford, 2005; Raggi et al., 2015; Rao et al., 1991). However, Uccelli, Specchia, Battaglia, and Miller (2009) conclude that a number of symptoms alone may not sufficiently explain job recession for PwMS, including fatigue. Studies since have cited fatigue as a key factor leading to work cessation, although indicate that it is a multifaceted issue, with fatigue playing an aggregate rather than independent role (Coyne, Boscoe, Currie, Landrian, & Wandstrat, 2015; Krause, Kern, Horntrich, & Ziemssen, 2013; R. D. Simmons, K. L. Tribe, & E. A. McDonald, 2010). Participants in this study discuss the impact of fatigue on their workplace experiences, although it is often noted in conjunction with adjustment strategies. This suggests fatigue itself may not lead to stopping work if managed successfully. Although symptom impact alone may not be a deciding factor in leaving work, PwMS may be more likely to leave work due to difficulties with managing symptoms in the workplace rather than work-related factors (Rex D. Simmons, Kate L. Tribe, & Elizabeth A. McDonald, 2010). Therefore, management of symptoms should be a priority for PwMS and employers working together to aid job retention.

When considering specific job demands that may lead to early retirement, a Danish study found a slightly increased risk linked to physical work (Pfleger et al., 2010). Participants of this study noted the stress associated with job demands, such as travelling at rush hour, or lack of occupational support structure. Chronic occupational stress has been shown to result in cognitive deficit and neurophysiological changes in otherwise healthy employees (Savic, 2015). Thus, PwMS may be all the more adversely affected by work-related stress. Further, high levels of stress may be linked to poor adjustment in MS regardless of disease severity (Dennison, Moss-Morris, & Chalder, 2009).

Job demands can influence motivation to remain in work. Theories of motivation such as expectancy theory may help to explain how job demands combined with MS impact can lead to withdrawal from paid work. Where an individual expects low rewards in comparison to the cost of remaining in work, they are less likely to be motivated to continue working (Wang & Shi, 2014). Similarly, Self-efficacy theory (Bandura, 1977, 1982) may help toward explaining the decision to leave work. Self-efficacy refers to beliefs about one’s capabilities, for example in coping with challenges or completing tasks. Self-efficacy has been shown to positively predict physical and social functioning, when accounting for MS-related impairments (Schmitt, Goverover, Deluca, & Chiaravalloti, 2014). Self-efficacy is also influenced by close interpersonal relationships (Bandura, 1982). PwMS who receive positive assurances from close others may feel more motivated to push through difficulties at work. Indeed, self-efficacy has been shown to play a significant mediating role in leaving work for PwMS (Ford, Wicks, Stroud, & Tennant, 2019). Participants in this study recount social support (or lack thereof) at different stages of their work experiences, such as making adjustments and the decision to retire.

Finally, as *Job demands* has been identified as a theme in this analysis, it is important to consider the relevance of the Job Demands-Resources Model (J D-R;Bakker & Demerouti, 2007). The J D-R model responds to critique and combines useful concepts of two previous stress models (demand-control model and effort-reward imbalance model) to apply a relevant theoretical model for the occupational setting. Where these previous models relied on limited variables which may not be applicable to a wide range of job types, the J D-R model simplifies the key principles into two general categories: job demands and job resources. Where demands outweigh resources, there is a negative effect on employee wellbeing, while increased resources can act as a buffer to these negative effects. Likewise, high level of job resources can increase work motivation. Bakker and Demerouti (2007) provide a compelling review of the literature that supports this model in various occupational settings. For PwMS, properties of their MS such as symptom impact or disease severity may create additional demands which counteract job resources. Comparisons can also be drawn between the J D-R model and Kirk-Brown & Van Dijk's (2014) empowerment model of workplace support for PwMS. Where the employer response is disability-focused, this constitutes a high job demand setting, whereas an ability-focused response produces low demand. Disability-focused responses which include discrimination or stigmatisation provide low resource, whereas paternalism includes some level of resource through social support (even if it is misplaced). Likewise, ability-focused response provides positive resources, and combined with the low demand, leads to the most positive work outcomes for wellbeing and motivation. Participants in this study noted various job demands which contributed to job strain. However, participants also identified strategies to reduce demand, or resources such as social support, that reduced this strain, even if not directly.

How resources are accessed might be explained by social exchange theory (Emerson, 1976). Where actions and reciprocal processes of exchange are hedonically positive, such as a work setting in which PwMS percieve high organisational support or feel valued at work, this may act as a catlyst to accessing further resources through ongoing positive interdependent exchange processes. However, where an employer response is disability-focused, this can create a hedonically negative social exchange, presenting barriers to beneficial resources.

MS trajectory also appeared to play a role in leaving work, when considered in conjunction with workplace policies. For example, Natalie found that due to the severe nature of her MS, her paid sick leave entitlement had been exhausted thus early retirement became a financial necessity. For other participants, periods of severe MS impact or a shift in MS course, such as progressing from relapsing-remitting to secondary progressive MS, contributed to the decision to cease work. Previous literature suggests that disease progression may contribute to workplace difficulties or early retirement for PwMS (Krause et al., 2013; Raggi et al., 2015). Although a full review of their impact is beyond the scope of this research, disease-modifying therapies (DMTs) have been shown to reduce progression of disability in MS, thus having a role to play in MS trajectory (e.g. Kallmann et al., 2019; Taheri, Sahraian, & Yousefi, 2019). Further, use of higher efficiency DMTs such as natalizumab and fingolimod have been associated with increased productivity and participation in employment (Chen et al., 2018). The increasing extent of available DMTs for PwMS is likely to be consistent with increased work participation.

Theme 2: Adjustment Strategies

Participants considered how development of suitable adjustment strategies had contributed to their workplace experiences and decision to leave work. Being able to implement successful strategies was helpful in continuing work. However, strategies for *Managing symptoms and fatigue* can ultimately include the need to step back from paid employment. Mobility problems, fatigue and EDSS score have been consistently linked to work related difficulties (Moore et al., 2013; Raggi et al., 2015). Strategies to manage symptoms often require a multifaceted approach. For example, fatigue may be influenced by factors such as depression and anxiety (Ford, Trigwell, & Johnson, 1998; Johansson, Ytterberg, Hillert, Holmqvist, & von Koch, 2008). Further, Butler, Thomas, Carolan, Silber, and Chalder (2019) identified a bidirectional relationship between anxiety and MS symptoms, with anxiety triggering symptoms of MS as well as MS symptoms increasing anxiety levels. Therefore, it is important to extricate the various components that may be contributing to certain symptoms to identify suitable management strategies early.

Financial planning appears to be an initial step in the process of leaving work for PwMS. This is consistent with the Temporal Process Model of Retirement, which follows three broad steps: retirement planning, retirement decision making, and, finally, retirement transition and adjustment (Wang & Shi, 2014). *Financial planning* forms part of retirement planning. Participants noted how previous financial decisions fit alongside their retirement decisions. Where participants had been able to secure additional financial stability, there was less negative feeling toward retirement. A review by Uccelli et al. (2009) found that financial considerations represented a significant differentiating factor between PwMS in work versus no longer in work, concluding that financial insecurity may play a motivating role in staying in work longer. Whilst financial insecurity may correspond to continued work participation, this may be at the detriment to factors such as wellbeing or quality of life.

Paid work is intrinsically linked with social value in the UK and in capitalist societies generally. Social value here refers to contributions that benefit the wider community or society, and the resulting self-value that is achieved through being able to provide these. Participants leaving work face a loss of the social value they achieve through paid employment. This requires a psychological adjustment as well as finding sources of social value in other components of life.

Foster (2007) contends that the current capitalist system reduces individuals to their labour value, and consistently undervalues people with disabilities as ‘less productive’. Although labour value may contribute only partially to social value, this does suggest that PwMS may experience a loss of social value before even leaving paid work. However, social value may still develop via social capital. Theories of social capital may differ slightly across disciplines, but the core concept suggests that value is created through interpersonal relations, as social interaction can provide resources and a means to achieve desired goals (Adler & Kwon, 2002). Participants in this study considered the importance of maintaining social interactions to provide value to their daily experiences.

Social capital can act as an important resource in social exchange processes (Hall & Widén-Wulff, 2008). However, for PwMS leaving work, there is a notable shift in exchange relationships which sees individuals move away from a potentially well-balanced interdependent organisational exchange relationship (i.e., their employment role) toward a broader social exchange dynamic with societal systems and structures (such as government welfare systems).

PwMS are faced with *managing transition* from onset of their MS. The experience of transition is particularly prominent for PwMS leaving or having recently left work; alongside the ongoing biological transitions of MS, the social transition from working to not working is a major life change.

Charmaz (1995) described two distinct coping styles people with chronic illness adopt: adapting and bracketing. Adapting acknowledges the chronic illness, and the changed sense of self that accompanies it, whereas bracketing involves compartmentalising the illness in an attempt to preserve a previous identity. People with relapsing-remitting MS may fluctuate between these two coping styles during periods of exacerbation and recovery (Barker, das Nair, Lincoln, & Hunt, 2014). As the MS trajectory progresses, it may become more difficult to utilize bracketing techniques. Further, PwMS who use bracketing as a coping strategy are less likely to seek relevant support or disclose their MS in the workplace.

Barker et al. (2014) consider the role of family in identity reconstruction following MS diagnosis, another major life change. This period of transition can lead to a stronger sense of self within the family unit. The family provides a secure social group for PwMS to adapt and adjust to MS as a part of their identity. Similarly, PwMS may utilise family support during the transition out of work to reconstruct their identity in a psychologically safe social environment. The increased sense of identity within the family setting is consistent with the prioritising of family time as a benefit of retirement. Participants in this study discussed the benefits of spending more time with family after leaving work. In their review of retirement research, (Wang & Shi, 2014) consider how this strengthened dedication to family fits to role theory; where the worker role is decreased in the retirement process, other roles may increase to compliment this, such as family member role.

Leaving work may offer an opportunity for PwMS to disentangle social and organisational exchange relationships. Regarding social exchange theory, Cropanzano, Anthony, Daniels and Hall (2017) note that there is an important distinction to be made between relationship types and forms of exchange (or transaction). Social relationships may differ from exchange relationships in a number of ways. Similarly, social transactions and exchange transactions can differ in how obligations are made and negotiated. Where organisational exchanges may need to rely on explicit bargaining, social exchanges are more likely to be built on trust and personal feelings of obligation. Where there is a mismatch (e.g., social transactions within an exchange relationship) this presents higher risk.

Further, participants in this study who were able to access strong social support through trust relationships both in and out of the workplace appeared to have a more positive experience of adjusting to leaving work. Skar, Folkestad, Smedal, and Grytten (2014) found that peer support through inpatient rehabilitation was beneficial to identity, validation and empowerment. Interacting with peers who had mutual understanding of MS experiences and who PwMS did not need to legitimise their MS to helped adaptation to post MS identity and adjusting to changes such as use of walking aids.

PwMS may manage their identity to avoid stigmatisation. Goffman (1978) conceptualises the presentation of self through interpersonal interactions using an analogy of the theatre, exploring how individuals utilize impression management to portray their social self. Goffman’s theories are based in social constructionist perspectives.

Social exchange theory (Emerson, 1976) poses that individuals continually act to balance perceived benefit against cost in their social interactions. As such, identity management may be a means to decrease the potential cost of stigmatisation, at the expense of social identity management.

Additional to social identity, occupational identity is the sense of self developed through occupational participation, i.e., how an individual habitually engages in meaningful activity (Kielhofner, 2002). Through the model of human occupation, Kielhofner explores how barriers to fulfilling occupational identity can be detrimental to psychological wellbeing.

Laliberte-Rudman (2011) note that there is a dialectical relationship between occupation and identity. Although occupation encompasses daily activity beyond paid work, this is relevant to PwMS no longer in work, who are managing their identity alongside a transition of leaving work. It is important that identity can be maintained in daily activities once paid work is no longer a main occupation. How individuals spend their time out of work is influential on identity, likewise, identity influences how individuals spend their time.

Phelan and Kinsella (2009) pose that current theories of occupational identity hold assumptions of the individual as central to identity formation, failing to recognise the collective. This is problematic in understanding occupational identity in wider cultural contexts. Thus, it is crucial to consider wider contexts when seeking to understand occupational identity development.

Barnes-Farrell (2003) considers retirement in relation to maintenance of self-image. This is relevant where PwMS may feel that their ability to do their job as well as they would like presents a barrier to positive self-image, thus placing ill-health retirement as a desirable alternative. Barnes-Farrell sets out two types of in-work role that individuals may take on; the ‘worker role’ which is focused on being productively employed, as well as the ‘organisational member role, which holds attachments to the specific organisation an individual is employed with, its rewards and structure. This distinction in roles can be seen in the participants in this study. For example, Nelly expresses a strong sense of identity in the specific work she has found, describing it as her “one” of jobs. Her activities since leaving work appear to be a maintenance of the identity that she held in this specific work role. On the other hand, in the in-work participant group (Chapter 4), one participant described how being in work was important to him, regardless of the specific job.

Theme 3: Dis/Empowerment In/Validation Matrix

Millen and Walker (2014) consider stigma of people with chronic illness through the concept of spoiled identity. First, they review how stigmatisation of illnesses has progressed from a sullied image of the person through religious purgatory to embodiment of illness itself to invalidate and devalue. They argue that despite public campaigns to reduce stigma, people with chronic illnesses may still be perceived as less deserving of care: “*To be labelled as having a chronic illness or disease is to be labelled as having an illness that is expensive and a burden on society*” (p.91). Such stigma may be internalized, resulting in individuals with chronic illness to withdraw from activities of daily living. To avoid this stigma, people with chronic illness may act to avoid detection by normal others. However, Millen and Walker argue that, despite continued stigmatisation of chronically ill persons, there is evidence that they are defying these negative perceptions, thus gaining freedom of previous dependence on society.

Participants describe experiences of invalidation and disempowerment at their previous place of work through not being heard. Invalidation has been shown to negatively impact mental wellbeing and social functioning in other invisible illnesses (Kool et al., 2010). Invalidation is a lack of belief, understanding or acceptance of something. PwMS may experience invalidation in the form of stigmatisation; this can range from undervaluing the impact of certain symptoms to a wider scepticism around MS as a condition. Invalidation of MS can be linked to power. According to Foucauldian theory, power lies in the requirement of action (Tremain, 2006). The act of invalidation contradicts any requirement of action in relation to equal opportunities.

Even where participants considered that their employer had validated the impact of their MS in the workplace, adjustments put forward by some employers displayed a lack of understanding or consideration for the employee’s perspective. Employer responses that focus too heavily on disability or what an employee cannot do at work are invalidating and disempowering (Kirk-Brown & Van Dijk, 2014). Encouraging open dialogue between employers and PwMS to develop a joint approach to working well with MS is necessary to reduce the risk of disempowerment in the workplace. Training tools that help employers to frame conversations around the skills and capabilities an employee can bring to their role and how best to support them may be beneficial in reducing disempowerment of PwMS at work. Further, the manager-employee relationship is influential in perceived sense of self-efficacy at work, which in turn affects performance and motivation (Bandura, 1982). Thus, engaging with employees to utilize and develop their specific skill sets also offers benefits to the employer by way of fostering a diverse and high-achieving workforce.

Empowerment is context-specific (Zimmerman, 1995). However, as a rule, at any level, empowerment involves an ability or a development of skills to use knowledge, access resources, and influence policy and change. The *authority voice* describes a situation by which an individual may be invalidated, but experience power and empowerment indirectly, for example, through a healthcare professional (HCP). Zimmerman (1995) points out that an individual can be empowered even without having the authority or power to assert change. According to his nomological network of psychological empowerment, 3 measurable components contribute to empowerment. The first, which Zimmerman classifies ‘intrapersonal’, includes a perception by the individual that they are capable in achieving a desired outcome. The second, ‘interactional’, requires that the individual has relevant knowledge of the contextual systems in place. Finally, the ‘behavioural’ component includes engagement with behaviours that lead to empowerment outcomes. Thus, utilizing the authority voice of the HCP meets these conditions of empowerment. However, the individual with MS has encountered invalidation of their experiences. Instead, the expertise of the HCP is accepted as a more valued form of knowledge.

Zimmerman’s (1995) model of empowerment holds to a central condition in parallel with theories of motivation such as the expectancy-valence model (Vroom, 1964) and Bandura’s (1982) self-efficacy theory; a perceived expectancy that the individual will be capable of achieving a desired outcome. Thus, utilizing exchange relationships such that PwMS are provided resources such as support, and social assurances may be a key contributor to PwMS achieving their desired work outcomes. Provision of such resources may be made possible through empowerment itself. Therefore, it is logical that empowerment may be linked with increased self-efficacy and motivation at work. Further investigation into these relationships should be considered.

Authenticity at work is a consequence of feeling validated and empowered. Empowerment can arise as a process or an outcome (Zimmerman, 1995); authenticity at work reflects an important empowerment outcome. Authenticity at work also suggests high psychological safety, which comprises feeling able to take interpersonal risks. Psychological safety perceptions may be influenced by employer responses to disclosure (Kirk-Brown & Van Dijk, 2014). Ability-focused responses are empowering and help employees with MS to feel valued as workers. Employees who feel valued experience higher self-worth (Sluss, Klimchak, & Holmes, 2008).

Theme 4: Social Relationships

Participants discussed the community of the workplace, and the loss they experienced on leaving that workplace. Burroughs and Eby (1998) attempted to define a framework and measurement tool for the construct of a ‘psychological sense of community in the workplace’. However, their work highlighted that this concept is particularly complex and multifaceted. That said, dimensions of a psychological sense of community at work outlined by Burroughs and Eby (1998) include co-worker support, emotional safety, sense of belonging, spiritual bond, team orientation, tolerance for individual differences, neighbourliness, sense of collectivism and reflection. Further, sense of community in the workplace was linked to job satisfaction and organisational citizenship behaviours. Thus, it is theoretically comprehensible that individuals who experience a stronger sense of community in their workplace may be more likely to stay in work longer, despite health challenges.

Burroughs and Eby (1998) define emotional safety as “*when members of the workplace community know how they can count on one another and on their leaders for support and honesty which inspires feelings of mutual trust and security*” (p.512). Similarly, Kirk-Brown and Van Dijk (2014) explore psychological safety, defined as “*the belief that it is safe to take interpersonal risks in the workplace and to discuss personal issues*” (p.1625). Kirk-Brown and Van Dijk (2014) found that when an employee with MS feels respected and more able to take interpersonal risks in the workplace, they are more likely to disclose their MS. This, in turn, creates better opportunities for support and suitable adjustments. Further, where social support is perceived at work, the coinciding sense of predictability may have positive implications for the somatic experience of chronic illness (Cohen & Wills, 1985).

In regard to co-worker support, Vera, Martínez, Lorente, and Chambel (2015) found that social support is a mediating factor in the relationship between work autonomy and work engagement. However, this effect was only meaningful when the social support stemmed from a supervisor rather than co-workers. Therefore, while co-worker support may be favourable in workplace experiences, it is unlikely to play a crucial role in employment outcomes.

Scott, Colquitt, Paddock, and Judge (2010) demonstrate that employees whose managers are supportive and empathetic are more likely to achieve their work goals. However, Foster and Fosh (2010) point out that even where managers are accommodating, the power dynamic between the chronically ill employee and their manager is unequal, not just due to employment hierarchy but in the wider social context.

Zaheer, McEvily, and Perrone (1998) define trust as "*the expectation that an actor (1) can be relied on to fulfil obligations, (2) will behave in a predictable manner and (3) will act and negotiate fairly when the possibility for opportunism is present*" (p. 143). Zaheer et al. (1998) go on to argue that robust trust relationships are beneficial in negotiations and reduce the likelihood of conflict.

Having trust relationships in the workplace appeared beneficial to participants in this study, in terms of having someone to disclose to and confide in. Strong social ties in the workplace can also be beneficial to social capital and career outcomes (Seibert, Kraimer, & Liden, 2001). Notably, managerial relationships can be important for employee self-worth (Deci, Connell, & Ryan, 1989). In her interview, Nelly discussed the importance of the employee-manager dynamic in the workplace for successful work stability.

Participants noted dichotomous responses from others to their MS in the workplace by way of either emotional engagement or emotional distancing. Similarly, Kirk-Brown and Van Dijk (2014) delineated organisational response to employees with MS as either ability-focused or disability-focused. Disability-focused responses fell into either stigmatisation or paternalism. Although well intentioned, paternalism resulted in low self-efficacy at work and poor psychological safety. In the present study, similarities can be seen in these types of responses. For example, Nelly noted one manager whose response she describes as 'the perfect textbook' answer, by which the manager did not make assumptions and could be regarded as 'ability focused'. On the other hand, some participants noted that their colleagues either distanced themselves (stigmatisation) or became emotionally engaged (paternalism) or empathetic. Grytten and Måseide (2006) noted a similar effect by which others either over-emphasised MS in an attempt to be tactful or ignored it. These processes of stigmatisation, though possibly well-intentioned, can serve to invalidate or disempower PwMS. Increasing awareness or visibility or MS may help to reduce this fear of the unknown in non-MSers and increase positive perceptions.

Morality featured in much of the interview discussions. Participants considered disclosure as a morality issue, of being honest with employers about potential future sickness or adjustment needs. However, a review by the Disability Rights Commission (2007) found that health and professionalism are commonly conflated, suggesting that requiring adjustments at work may lead to perceptions of not being a good worker.

Interestingly, participants of this study considered disclosure as linked with being a good worker and performing the duties of the role; either disclosure opened pathways to adjustments to allow duties to be completed, or it informed employers to allow for organisational restructuring. In either case, the concept of being a good worker includes assuming a sense of responsibility for the needs of the organisation.

Foster and Williams (2014) provide a detailed review of how ideal worker norms impact people with disabilities, for example, through stigmatisation. Specifically, flexibility stigma is a product of ideal worker norms (Kmec, O'Connor, & Schieman, 2014). By this, employees who are not willing or are unable to meet norms such as extended working hours, are labelled as uncooperative and having a poor work ethic regardless of how these norms contribute to their work goals. Further, uncertainty around flexibility requirements can increase the likelihood of flexibility stigma (Foster & Williams, 2014). Thus, PwMS are likely to be at increased risk to flexibility stigma.

It is worth considering that people with disabilities in the workplace may also suffer barriers due to their own expectations of discrimination (Foster & Williams, 2014). This may reflect principles of role theory, with PwMS adapting their sense of identity to conform with social constructs of the ‘disabled’ role (Biddle, 1986). Indeed, role theory may also be useful in understanding retirement decisions. For example, participants in this study considered their role within the family, such as providing financial support, when making retirement decisions. Szinovacz, DeViney, and Davey (2001) found that workers providing financial support to children outside the home may be less likely to retire. Therefore, identity and role are central to how PwMS experience their employment and their retirement. Further, employer responses may serve to reinforce perceived threats to, and negative perceptions of self-identity held by PwMS. Employers and PwMS involved in managing adjustments or transitions regarding work should consider how such processes can instead validate positive self-identities and roles.

Social exchange theory posits that social interactions carry implicit value (Emerson, 1976). In particular, reciprocity of social exchange can be seen as a moral norm (Cropanzano & Mitchell, 2016). This concept of moral obligation to ensure mutuality in social exchanges is reflected by participants in this study. Being a good worker included a ‘willingness from both sides’ through *reciprocity*, discussed below, and participants felt morally compelled to maintain this.

This sense of moral obligation might also be explained with theories of occupational commitment (Johnson, Chang, & Yang, 2010). Normative commitment refers to the sense of obligation that employees feel toward their employer. Further, introjection may see employees acting to meet perceived obligations to reduce feelings of guilt and anxiety.

Finally, regulatory focus theory (Brockner & Higgins, 2001; Higgins, 1998) posits that individual motivation can be either ‘promotion-focused’ or ‘prevention-focused’. While promotion-focused individuals are motivated by developing toward an ideal self and seeking gains, prevention-focused individuals are motivated by the sense of ‘ought to’ and avoiding losses. Perceptions of responsibility are central to prevention-focused motivation. The current legislative framework, and by extension organisational culture, in the UK appears to push PwMS toward a prevention-focused approach, in that, their occupational outcomes are often framed as avoiding potential losses, rather than achieving potential gains. Regulatory-focus theory also has implications for how PwMS respond emotionally to workplace barriers (Brockner & Higgins, 2001); predominantly promotion-focused individuals may experience dejection whereas prevention-focused individuals tend toward agitation.

Theme 5: Organisational culture

Participants discuss the concept of ‘a willingness on both sides’, termed in this analysis as *Reciprocity*. Nelly considers this as a strategy of interpersonal relationship management, and notes that although she has legislative rights to adjustments at work, it is beneficial to nurture these interpersonal dynamics. This strategy is comparable to the Interpersonal Threat Regulation model (Williams, 2007), which looks at how interpersonal trust in organisational settings can be developed. The model addresses how perspective taking, threat-reducing behaviours and reflection can be useful in building interpersonal trust and reducing threat responses. Such strategies can be beneficial for both employers and employees when managing MS in the workplace. Williams (2007) contends that individuals who perceive a threat to their self-image are likely to avoid requesting help when they need it. Managing interpersonal dynamics and threat perceptions in the workplace may be key to encouraging help-seeking behaviours and reducing barriers for PwMS in work. The concept of reciprocity is also consonant with Social Exchange Theory (Emerson, 1976). Cropanzano and Mitchell (2016) assert that reciprocity, as a tenet of social exchange theory, includes interdependent exchange processes. That is, both sides of an organisational relationship will contribute to the progress of the exchanges or social transactions. Another type of reciprocity noted by Cropanzano and Mitchell (2016) is a cultural belief of moral justice, i.e., "*over time all exchanges reach a fair equilibrium*" (p.875). Although not as commonly discussed by participants in this study as other aspects of reciprocity, some did consider that previous performance as a good worker had played in their favour when seeking support from employers. Still, morality did feature in disclosure decisions, such that fair social exchange included honesty and openness. Finally, reciprocity can be distinguished as a moral norm or obligation and can have influence on employee satisfaction or perceived support (Cropazano & Mitchell, 2016). This is reflected by participants of this study strongly; Naomi and Natalie both describe feeling that their efforts are not reciprocated in the workplace and this has contributed to a reduced sense of loyalty to their employer. On the other hand, Nicola seemed to feel her employer acted in a way that she could not feasibly reciprocate due to her MS, therefore causing an imbalance which felt unjust. Thus, reciprocity is bidirectional and seems to require an equal balance regardless of level of effort or contribution. An imbalance in the exchange dynamic in either direction can create discomfort in the workplace and lead to negative work experiences or early work cessation for PwMS.

Szinovacz (2013) considered retirement as a multilevel phenomenon. It is important to consider macro-, meso- and micro-level influences on retirement when considering the experiences of PwMS. Factors such a state pension age, perceptions of retirement and policies related to retirement may impact these experiences. In particular, PwMS may be faced with defying social norms of retirement age or receive a reduced state pension due to early or medical retirement. Participants discussed to what extent their leaving work matched with their expectations about when they would retire. Retiring at or after their personal expected age to do so seemed to have a positive impact on individual's feelings toward having retired. Despite adjusting his expectations about when he would need to leave work, Neil described how he surpassed these expectations which seemed to make the decision to and transition of retiring a positive experience. Likewise, Naomi had met her goals of successfully continuing to work following diagnosis, which empowered her in making the decision to retire. As per social learning theory, achieving or surpassing personal goals can have a positive motivational effect for individuals (Bandura & Cervone, 1983).

Further, PwMS who exhibit adaptive goal adjustment capacities following diagnosis, progression or other MS-related challenges may experience better quality of life outcomes (Barlow, Wrosch, & McGrath, 2020). Despite goal disengagement relating to adaptive goal adjustment, Barlow et al. (2020) identify that people at high risk for depressive symptoms may also be more likely to disengage with unattainable goals as a means of conserving resources for new goal engagement. It is imperative, therefore, that goal adjustment interventions focus on strategies to engage with attainable goals.

The life course perspective considers the interplay between social contextual factors and biological health outcomes (Burton-Jeangros, Cullati, Sacker, & Blane, 2015). Specifically, Moen (1996) explored the health impact of retirement in terms of the life course perspective. Factors such as age, not just as a biological circumstance but in terms of social meaning and role, are important in how the retirement transition is experienced. Retirement that begins at a culturally conventional age may be influential in how health is experienced following retirement; most notably, McGoldrick and Cooper (as cited in Moen, 1996) found that individuals who retire for health reasons can feel better for leaving work. Thus, PwMS who are able to fulfil their expectations of working to a socially conventional retirement age may have more positive post-retirement experiences, even where physical health has declined.

Theme 6: Locus of control

Uncertainty is embedded in the experience of living with MS. Feelings of uncertainty may be negatively associated with adjustment in MS (Dennison et al, 2009).

Moreover, individuals may differ in their tolerance toward uncertainty (Freeston, Rhéaume, Letarte, Dugas, & Ladouceur, 1994). Individuals with a low tolerance to uncertainty may have lower confidence in their problem-solving abilities as well as a reduced sense of control (Dugas, Letarte, Rhéaume, Freeston, & Ladouceur, 1995). Further, intolerance to uncertainty mediates the relationship between external locus of control and trait anxiety (Song & Li, 2017) whereas higher tolerance to uncertainty has been associated with higher levels of self-efficacy (Tingey, 2020). Nevertheless, tolerance to uncertainty is modifiable and PwMS are likely to benefit from interventions focused on this (Alschuler & Beier, 2015).

Participants considered to what extent their retirement was a voluntary decision, and the wider sense of control they felt in relation to their MS. Conceptualisation of retirement as a decision-making process may implement various key theories. Rational choice theory suggests that the decision to retire will be a result of the benefits of retirement being preferable to the benefits of continuing to work (Wang & Shi, 2014). Participants in this study discuss their process of weighing up the relative benefits of retiring versus continuing to work. For example, Naomi recalls that her decision to retire was influenced by the realisation that she could continue to receive an acceptable income and no longer face the stresses of her job. For others, the costs of staying in work became greater, thus tipping the scale. Similarly, expectancy theory posits that where the expected rewards of continuing to work are low, for example due to health impact, individuals are more likely to pursue retirement instead (Wang & Shi, 2014). Unfortunately, as some participants pertained in this study, retirement is not necessarily a voluntary decision. Natalie described that due to the severity of her MS trajectory, retirement felt imposed on her and there was little time for a decision-making process. Natalie's account of her severe rate of relapses is suggestive of a chaotic illness narrative

(Frank, 2013). Illness narratives can follow one of three main story types: restitution, chaos and quest journeys. The chaos narrative indicates poor self-determination and has negative consequences for psychological wellbeing.

Rotter (1966) conceptualised that individuals perceive a sense of control over their experiences as either internally influenced (internal locus of control) or externally influenced (external locus of control). By this, individuals with an internal locus of control feel that their behaviours and actions can directly impact rewards or reinforcements. Similarly, self-determination refers to the sense of control an individual has over their own life. Self-determination theory states that individuals have three basic universal needs – autonomy, competence and relatedness (Deci et al., 1989; Deci & Ryan, 2008). Feeling a low sense of control can be demotivational for individuals (Bandura, 1982). However, increasing job autonomy can enhance internal locus of control (Wu, Griffin, & Parker, 2015). Further, internal locus of control has been positively associated with outcomes relevant to work, including job satisfaction, job motivation, as well as mental wellbeing, coping and health perceptions (Ng, Sorensen, & Eby, 2006). Thus, interventions that promote job autonomy may have a positive impact on job retention as well as retirement experiences for PwMS.

Barnes-Farrell (2003) considers that in making retirement choices, individuals will prefer the role that allows them to maintain the highest sense of personal control in their lives. Different factors may affect which elicits more personal control, such as organisational culture or empowerment at work.

Naomi discusses feeling in control by continuing to exercise and look after her fitness. Exercise is empowering for her and helps maintain an important aspect of her identity. While exercise can be empowering for PwMS and offers many benefits, Adamson, Adamson, Littlefield, and Motl (2018) pose that it is important that this does not lead to a rejection of disabled identity where this may be beneficial to the individual.

Strengths and Limitations

This group of PwMS no longer in paid employment includes an office administrator, a teacher, a medical professional, a career coach, a cleaning supervisor, and a nursing matron. Participants were from a mix of private and public sector most recent workplaces, including white, blue, and pink-collar work types. Previous employing organisations ranged from small to large. Therefore, this group includes a range of occupational experiences. Participants also included representatives from various MS trajectories, which included relapsing-remitting, primary progressive, secondary progressive and rapidly evolving severe MS.

In total, 5 females and only 1 male participated in interviews. However, the MS population sees a ratio of 2.4 affecting females to males (Mackenzie, Morant, Bloomfield, MacDonald, & O'Riordan, 2014), therefore this study would have benefitted from a greater proportion of the male perspective. Likewise, this study lacked perspective from marginalised ethnic groups, with all participants in this subset self- reporting as Caucasian.

Concluding Remarks

This chapter explored employment and MS from the perspective of PwMS who had recently left work (i.e., within the last 12 months). The six key themes identified, *Dispositional Properties, Adjustment strategies,* *Dis/Empowerment In/validation matrix, Social Relationships, Organisational Culture and Locus of Control* encompass the mechanisms that contribute to facilitators and barriers to working with MS in addition to the process of leaving paid work.

Managing paid work with MS is a complex and multi-faceted issue. The transition of leaving work can also carry navigational challenges. Specific dispositional factors, such as MS symptoms, trajectory and job demand clearly add to the barriers of continued employment, although may be too individualistic to form a comprehensive intervention strategy around. However, it is reasonable to conclude that where overall job demand and symptom impact outweigh job resources and benefits, PwMS are more likely to leave paid work. Hence, the JD-R model taken into consideration with MS symptom impact may form a useful toolkit in identifying specific factors that contribute to an individual's work instability. Identifying such factors is useful to developing management strategies. Strategies to manage symptom impact should consider the interrelationship between multiple symptoms PwMS may be experiencing. Further, identifying and considering these early in the MS journey is likely to reduce risk of leaving work early. Beyond symptom management, PwMS who are considering leaving work must also manage their financial and social transitions. While financial insecurity may result in continued work participation, this may not correspond with coveted employment situations.

Developing adaptive coping styles may be useful to PwMS in managing transitions. As PwMS begin to consider transitioning out of paid work, it may be relevant to consider their self-identity and how this may be affected by such a transition. Preparing in advance for transition and adjustments to self-identity in a mindful way could be helpful in avoiding personal dilemma during or after the retirement period.

PwMS reflected on experiences of invalidation and disempowerment as factors that influenced their withdrawal from paid work. It is not unexpected that invalidation and disempowerment will have a negative impact on factors such as wellbeing in the workplace. However, this analysis adds further evidence to the complex matrix of validation and empowerment settings that PwMS may find themselves in. Most notably, where one occurs without the other, such as in supportive disempowerment, it can be difficult for individuals in the moment to disentangle why, despite either being validated or empowered, they continue to feel unheard.

This chapter highlights the central role paid employment plays in social connections; in the UK's capitalist system, the workplace forms a key setting for establishing communities. Having left work, PwMS became distinctly aware of the community that they had left with it. Further, this chapter strengthens the importance of social support in the workplace. In particularly, high psychological safety through trust relationships and ability-focused responses may act as facilitators for PwMS to continue working well. Notably, social support has a positive impact on work engagement, autonomy, and self-efficacy.

Social exchange theory (Emerson, 1976) offers a useful framework to understand how these processes might play out. Indeed, core principles of social exchange theory, such as reciprocity, expectations and social relationships are evident in the model (Figure 5.1). Developing strategies to manage social relationships, including fostering reciprocity, is likely to be beneficial to PwMS wanting to stay in work as well as employers seeking to retain their workforce. Building strong interpersonal relationships can reduce threat perceptions such that PwMS may be more likely to seek and receive relevant support. However, employers should be cautious of over-offering in the exchange to a point that employees with MS feel that reciprocity on their part becomes untenable.

This analysis provides additional support for a relationship between goal attainment and wellbeing, in regard to personal employment outcomes. Meeting personal goal expectations of retirement age, whether this was in accordance with social norms or adjusted expectations, may also influence on-going health perceptions. This points to a suitability for interventions focused on goal-adjustment strategies for PwMS considering leaving work.

This analysis conceptualises retirement as a decision-making process. It highlights, however, that PwMS may not feel that the decision to retire occurs entirely in their control. Interventions aimed at increasing sense of control, such as through autonomy, may improve psychological outcomes following retirement as well as help PwMS who want to stay in work. Finally, interventions focused on tolerance to uncertainty are likely to be beneficial to PwMS, in work and beyond work.

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Chapter 6: Analysis: Professionals

Introduction

For this analysis set, ‘Professionals’ are those who have a professional relationship with people with MS (PwMS), thus this includes data from health professionals as well as employer representatives.

Employment is linked to health-related quality of life (Chung-Yi et al., 2015), thus may be of interest to healthcare professionals who are managing the health concerns of people with MS. Rothwell, McDowell, Wong, and Dorman (1997) found that patients with MS and their healthcare providers may prioritise health domains differently when assessing quality of life. An opportunity to progress the dialogue so that healthcare providers can better understand what is important to their patients may be beneficial for both parties.

The role of employer representatives in managing work outcomes for PwMS is conceivably vital. Employer representatives may be apprehensive about drawing negative attention to employees with disabilities, and as a result, are less likely to offer adequate support in the workplace (Kulkarni & Valk, 2010). Foster (2007) found that despite legislative protections in the UK, employees with disabilities faced significant social barriers to acquiring suitable workplace adjustments. A lack of support was attributed to line managers’ lack of training or understanding about disabilities. Larger or public sector employers in Britain are more likely to abide by legislation regarding disability discrimination in the workplace (Hoque & Noon, 2004). In the US, PwMS specifically are more likely to experience workplace discrimination than other employees with disabilities (Rumrill, Roessler, McMahon, & Fitzgerald, 2005). Understanding factors that account for these differences could be useful in understanding and preventing employment barriers for PwMS.

This chapter explores the experiences of employers and relevant health professionals who are working with PwMS to facilitate job retention. Limitations and facilitators to job retention for PwMS in the context of national and local policies are also considered, to help build a picture of what might contribute to successful intervention strategies for PwMS who want to stay in paid work.

Methods

Participants and Recruitment

Eight public sector HCPs and two employer representatives took part in research interviews. HCPs covered a range of specialities, as detailed in the Methodology chapter. The employer representatives were both in public sector work. Purposive sampling was used in order to maximise saturation of the potential range of specialists involved in the health management of PwMS. Despite extensive recruitment efforts, employers were notably difficult to recruit to this study. As part of the agreed protocol, researchers could ask participants with MS to recommend an employer for participation, if they felt comfortable to do so. However, despite interview questions not asking for information on specific employees, this could understandably be problematic, particularly as individuals may be the only employee with MS in the work team.

Data Collection

Semi-structured interviews were used and supplemented by a short pre-interview survey which collected basic demographic and employment details (Appendix B). Interview guides for HCPs and Employer representatives differed slightly in phrasing and questions, but topics covered were comparable (Appendices C.2, C.3). This was to ensure the questions were relevant to the experiences the participant may have had with PwMS under their care or management. The interview guides began with broad questions such as “Can you tell me a bit about your role?” and went on to cover topics such as disclosure of MS at work, sources of support for PwMS in work, potential barriers and facilitators to employment for people with MS, government and organisational policies related to PwMS in work, sources of support for professionals managing PwMS and PwMS leaving paid work. Questions were phrased in a way so as to avoid any leading language. Participants were encouraged to give further detail in order to avoid assumptions on the part of the interviewer, for example, explaining why they used particular words or phrases. HCP interviews lasted between 54 minutes and 1 hour 55 minutes, with an average of 59 minutes. Employer interviews lasted between 34 minutes and 38 minutes, averaging 36 minutes.

Data Analysis

Data were analysed using critical grounded theory, as described in the Methodology chapter.

Analysis and Model

Five main themes were identified, with a total of 17 sub-themes. The main themes were *Knowledge flow, Structures of support, Capacity for support, (Three-legged) responsibility stool* and *Life journey.*

Despite the ‘retroductive spiral’ method of analysis used in critical grounded theory, in which the researcher moves back and forth between data-led and literature-led conceptualisations, this analysis will be presented first with the more grounded detail, graduating toward a comprehensive exposition of the conceptual mechanisms at work. A descriptive overview of the model (as shown in Figure 6.1) is provided. The themes and sub-themes are then explored in further detail, before considering theoretical evaluations and how this analysis fits alongside other relevant literature.

Healthcare professionals and employers as distinct groups do face unique challenges when trying to support PwMS in the workplace. For example, the theme *Life Journey* features more heavily in the interviews of health professionals, with a strong focus on managing MS as a journey, as well as recognising the multi-faceted challenges and benefits paid employment can provide. While employers may recognise the benefits of *Meaningful engagement* through paid work as part of the *Life Journey,* this is generally organisation-centric rather than a holistic approach to the role of work as a meaningful method of engagement in an overarching narrative. This is not unusual considering the priorities of each group; the goals of the HCP stem from a person-focused approach to managing MS in all parts of life, whereas an employer is acting within their role as a manager specifically to employment matters.

Consequently, the systems in which these different professionals are operating appear to be similar or have mutual influences. As such, the model presented below incorporates health professionals and employer representatives as a single model.

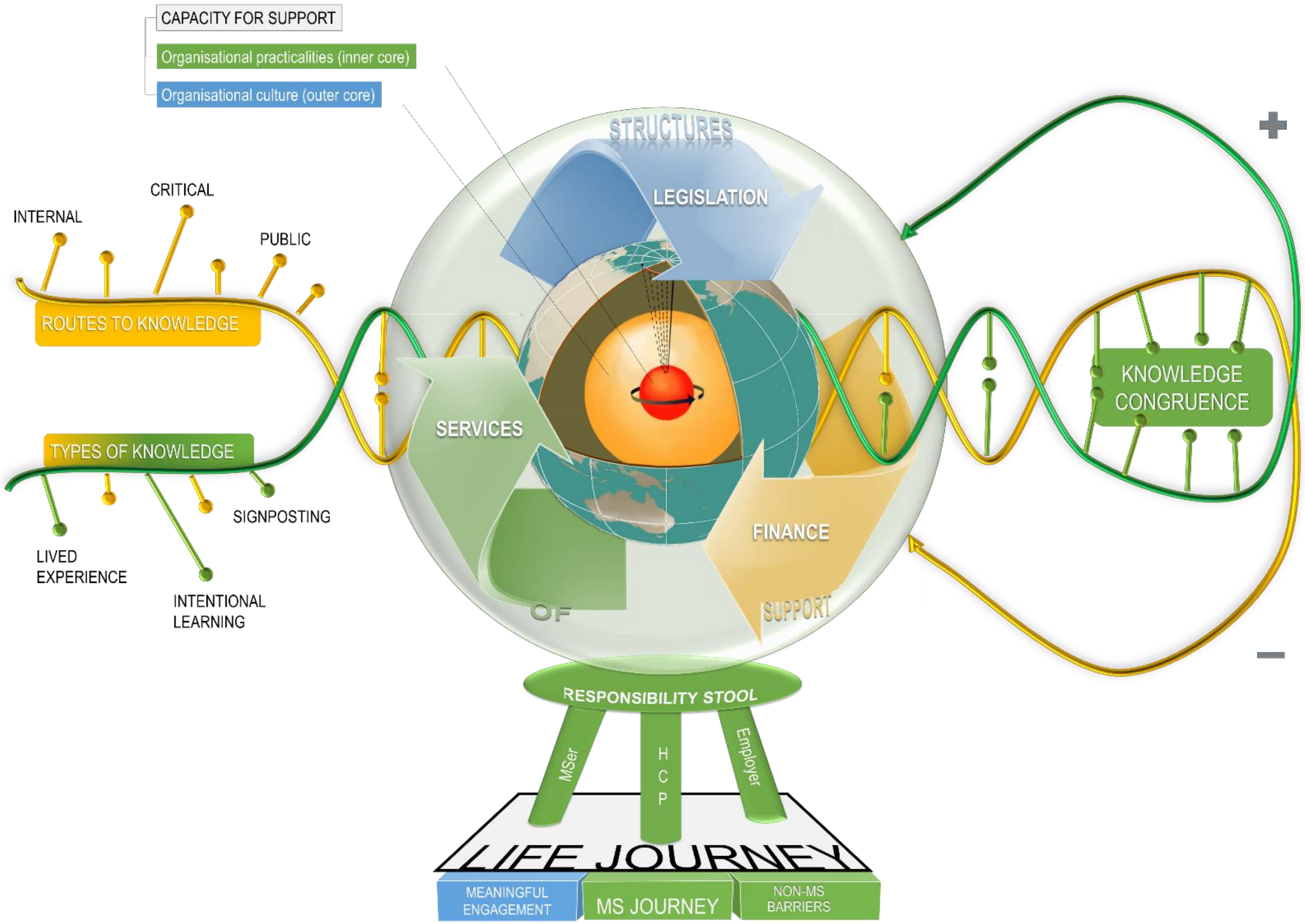

Figure 6.1 – Model of the experience of professionals managing PwMS in paid employment

Descriptive Overview of the Model

The Professional model rests on the foundations of the *Life Journey*. This represents the underlying mechanisms on which the working world is built. *Meaningful engagement* encompasses a societal concept that paid employment can fulfil a human social need to engage actively in the society that surrounds us. PwMS are also managing their work role specifically within the circumstances of their *MS journey*. As well as the specific challenges of MS, employees may be facing barriers to successful employment not related to their condition at all which further complicate their experiences. Grounded in this backdrop of the *Life Journey* is the *three-legged responsibility stool*, which is upheld by the three distinct groups involved: the *individual with MS*, *HCP*s and the *Employer*. Professionals recognise that the responsibility of successful employment falls to each of these groups and requires a joint approach. The analogy of the three-legged stool has been used previously to represent the necessity of all three legs (each presenting a distinct input) to be present and structurally balanced (DeWitt, 1996).

Resting on this figurative responsibility stool, is the world of work, within an atmosphere of *Structures of support*. The sub-themes of *Finance, Services* and *Legislation* create an interrelated triad of mechanisms which affect one another bi-directionally. *Legislation* at the macro-level, influences and is influenced by *Services* and *Finance*.

Routes to knowledge and Types of knowledge act as mediating inputs to *Knowledge congruence*, which can have either a positive or a negative output. The output of this *Knowledge congruence* feeds back into the structural atmosphere (*Structures of support*), creating influence on social policy, social environment and support mechanisms.

At the core of the world of work lies the *Capacity for support*. This metaphorical core, like the Earth, is made up of an inner (rigid) core, and an outer (flowing) core. The inner core of *Organisational practicalities* is difficult to move or alter and is based in a realist perspective of a fixed reality. The outer core is molten, free-flowing, and can be subject to movement; *Organisational culture*. This exists in a socially constructed and perceived form. The two elements move and interact against one another. Like the geophysical theory of the Dynamo mechanism (in which the movement of the Earth’s core generates a magnetic field), when these interactions occur in a certain way, a magnetic field (atmosphere) provides stability at the surface. On Earth, the magnetic field provides a protective atmosphere from solar winds, as well as guiding nature through the seasons (e.g., migration effects). However, variations in this relationship can lead to major disruption. If *Capacity for support* is the Earth’s core, the ‘magnetic field’ generated is a secure work environment.

Theme 1: Knowledge Flow

Knowledge held by individuals and groups within society plays a key role in social interactions. There are many different *Types of knowledge* which can influence assumptions such as those held about individuals with MS, what makes a good employee, or even what disability means.

There are also varying *Routes to knowledge*. Possibly the most common and earliest established process is through *Lived experience*. Our individual experiences can shape the truths we hold and form a framework for how we perceive the world. *Critical knowledge* can be shared through education systems and objective analysis methods. Such techniques to extend knowledge allow professionals to develop expertise and skills for further learning. In addition to knowing how to find knowledge through *Intentional learning*, individuals may access relevant information via *Signposting* to a group or individual with specific expertise. This multi-disciplinary approach allows knowledge resources to become vast while simultaneously maintaining specialist expertise in given domains.

Occupational Health departments may be very well placed to help employees with MS as they are employee advocates with training in healthcare management, but also have specific knowledge about relevant employment laws and policies.

Theme 1: Knowledge Flow; Sub-theme 1: Types of Knowledge (micro)

While there can be several types of knowledge, this analysis highlights three which were particularly evident in the professional interviews. These are *Internal knowledge*, *Critical knowledge* and *Public knowledge* which relate to micro-, meso- and macro- levels of society, respectively. Knowledge type can range from subjective in nature to more objective knowledge.

Theme 1: Knowledge Flow; Sub-theme 1: Types of Knowledge; Sub-sub-theme 1: Internal Knowledge (micro)

At the micro-level, all sentient living things hold at least some *Internal knowledge*, which logically affects their interactions with and understanding of the world. For professionals managing employees with MS, part of this management may involve working with differences in internal knowledge – either knowledge held by themselves or by others. *Internal knowledge* is formed via subjective interpretations of reality. This knowledge is constructed by our personal experiences and inner dialogue. As such, one person’s truth or understanding of a concept may not correspond with another. In the employment setting, this can create challenges for PwMS, when faced with colleagues, employers or even support agencies whose respective internal knowledge of MS does not correspond to individual experiences.

From a more general standpoint, MS does not often fit to a commonly construed narrative of illness; it can be difficult for colleagues and employers to understand that MS does not follow this typical sequence of illness followed by recovery.

> *"I guess it's tricky isn't it with something like relapsing remitting MS because people have just a vague knowledge of what it is, you know, whether somebody's in an active relapse or not will affect how their colleagues and how the employers think about the condition and then when they get better or they're in remission people are then like "oh you're better now, that's great, you know, brilliant, you're, you know, seems like there's nothing wrong" Henry HCP*

Further, even where chronic conditions may be well-understood, the nuances of MS can be difficult for those with less experience of it to recognise.

> *"…because I think a lot of people have this picture either of one extreme to the other and think, somebody's in a wheelchair, unable to do anything, really disabled with MS, or they just don't know what MS is…" Harriet HCP*

In particular, internal knowledge of MS may be constructed from personal experiences which are relevant for one case but not all. This can influence the response to a disclosure of MS; whether it is proportionate as well as whether it is positive or negative.

> *"…it depends on the personal experience from their friends or family members, rather than per se education-wise. So if a senior person knows a person with MS his approach to a patient with MS is different to a person who has never seen a patient with MS and knows nothing about MS. I think it's mostly personal, rather than the educational part." Howard HCP*

A major factor which appears to contribute to the stigmatisation and issues surrounding legitimisation of MS is invisible symptoms. It seems that visual cues are given more validity; a literal take on the idiom "I'll believe it when I see it".

> *"...so if somebody comes in on a mobility scooter and, you know, they say "do you know what, we've got a nice office downstairs, we're going to give them that one because they can't get up the stairs", people can understand that, they can understand it on an intellectual level and I think most of them have got the imagination to know that if they made snippy comments about that they're going to be perceived as, you know, a bad person." Hannah HCP*

Hannah continues to explain that this is not generally the case for non-visual symptoms of MS, which can lead to resentment by colleagues when accommodated for. In particular, fatigue is a common symptom that non-MS employees struggle to empathise with. This debilitating effect of MS is often misconstrued as simply feeling tired.

An interesting challenge this presents is in the case of discrimination and employment laws; the notably vague concept of "reasonable adjustments" can be interpreted quite differently by individuals or employers. This can result in a mismatch for what is expected, be this under- or over-estimating the accommodations required.

> *"I think that's the word, reasonable, and that's the word that might make the difference to the individual, so an individual manager might interpret*

> *reasonable adjustments differently from a manager who's more empathetic…." Harriet HCP*

Not only can this internal knowledge affect the response of employers, and even health care professionals, but the individual with MS may experience their conditions differently based on their personal conceptions. Despite empirical assumptions of medical knowledge (which it can be argued is critical and objective), PwMS may be able to determine the impact of their symptoms to some degree.

> *"…this is where it is where it's kind of profoundly psychological because the medics and the specialist nurses may be correctly of the opinion that this person might need to use a wheelchair or it might be in their interest, you know, it's not actually for anyone to say apart from the individual who we're talking about, you know, whether they need to or whether they want to but, well whether they want to, yeah, but the person I have in mind is absolutely adamant that's not going to happen until D-Day…" Henry HCP*

Theme 1: Knowledge Flow; Sub-theme 1: Types of Knowledge; Sub-sub-theme 2: Critical Knowledge (meso)

Critical knowledge is that which is formed objectively through empirical evidence. Online resources such as charity websites, as well as legislation can help to guide HCPs in matters regarding MS and work. Different people may have different specialist knowledge, for example, an MS nurse has clinical knowledge while an employment lawyer has legislative knowledge.

> *"…we look at ways we can support them, you know, through advice from occupational health, the occupational health physicians, or sometimes from our health and safety advisers, or as I say Access to Work as well." Elizabeth Employer*

Accessing relevant and high-quality critical knowledge can be beneficial for PwMS, employers and HCPs when managing work and MS. Hilary explains the benefits of experts in different fields of knowledge working together to share their relative knowledge.

> *"I'm just trying to say can we work together; you know the policies, you know what needs to be happening on your end but I know MS and I know how it affects the person so they might even say, oh we've got someone else with MS, we know what we're doing. Yeah, but it's different, every person is different with MS and how it affects one person will be very different so again, I'll always try and explain that to them." Hilary HCP*

It can be detrimental when individuals or employers share false assumptions due to conflating internal knowledge with critical knowledge. With the advancement of communication technologies (i.e., online sharing), quality critical knowledge can sometimes become muddled with subjective or biased information.

> *"Forums can be good, but I think the one thing about forums, for instance, is the fact that it's not always from a healthcare professional and they*

> *don't always understand the background to treatments and suchlike, so therefore people might think they're not receiving a treatment that they're entitled to, that kind of thing, so that can be a bad thing." Harriet HCP*

Theme 1: Knowledge Flow; Sub-theme 1: Types of Knowledge; Sub-sub-theme 3: Public Knowledge (macro)

Knowledge is readily available in the information age. Despite the risks mentioned above, this ready access to information can be useful in raising awareness of MS, helping to reduce stigma or negative work events.

> *"…people with disabilities are becoming more and more visible, you know, they're represented on television so you've got things like The Last Leg, the Paralympics are much, much bigger than they ever used to be, so I think they're less astonished to see people with disabilities in the workplace generally" Hannah HCP*

Normalising MS through media and public events can help to abate disproportioned responses, which in their own right can create a challenging work environment for PwMS. Creating an open dialogue in which people feel comfortable to talk about topics which may have been previously taboo is likely to have a positive impact on the wellbeing of society overall.

> *"I think something's changed after the 2012 Olympics and the Paralympics in the way that culturally we seem to have become more open to talking about disability…" Henry HCP*

Going a step further in hosting awareness campaigns can open avenues for employers to explore and learn more about MS and strategies for successful workplace adjustments.

> *"I like the fact that we have a week of MS, for MS now, because I think that kind of publicises things, and I think that helps if an employer has somebody with MS, they might look into it a little bit more because it's heightened by public knowledge" Harriet HCP*

Theme 1: Knowledge Flow; Sub-theme 2: Routes to Knowledge (micro, meso)

Access to various types of knowledge has increased drastically since the creation of the World Wide Web. While this has benefits, such as increased awareness and accessible learning, there is also the risk of poor quality, or highly subjective information being disseminated.

The *Routes to knowledge* sub-theme deals with how individuals attain their knowledge, which plays an important role in determining quality or objectivity of this knowledge. The analysis highlights three potential routes to access knowledge; *Lived experience, Signposting* and *Intentional learning*. These routes range from highly subjective, micro-level pathways, through meso-level signposting, to sourcing information via macro-level institutions (e.g., education systems) in an act of *intentional learning*.

Theme 1: Knowledge Flow; Sub-theme: Routes to Knowledge; Sub-sub-theme: Lived Experience (micro)

Personal experiences play an important role in information gathering for all sentient beings. From birth, infants learn how to interpret the world around them through lived experience. This forms our *internal knowledge*. Within the professional data set, HCPs feel that a lot of valuable knowledge is learned "on the job".

> *"I think it's been more when I'm actually in the moment and with a person, you know, it's kind of learning from individual to individual, from experience to experience, I think that's been the most important for me, because I think you can read and kind of understand where, you know, these things lie, but until you're sat there with a person, you don't necessarily know what you're going to say or do." Harriet HCP*

As well as being able to learn from their own personal experiences, HCPs utilize the experiences of PwMS to help them offer information to other patients.

> *"…this is just a part of what you kind of learn from day to day, mostly from patients really […] So they teach me, they taught me how to advise other patients." Howard HCP*

As well as lived experience being a useful tool of learning for HCPs, individuals with MS may need to experience their condition in order to adjust and update their understanding of how MS affects them and their work.

> *"…self-identity is just an enormous thing that comes up in my experience of how MS affects people over time. There comes this point where there's this new me that they don't really recognise in comparison to old me and there's this kind of gap between them and people are left with these questions as to "well who am I?" you know, their sense of self comes under threat." Henry HCP*

Henry goes on to discuss the benefits of exploring this new sense of self with the guidance of a health professional, and by doing so, adjusting to an updated identity. This process of adjustment, through exploring old and new knowledge of self, ties to the *Adjustment process* theme in the MS working group model.

In the case of employers, having previous knowledge of MS through personal experiences can help to make navigating the workplace less challenging for individuals with MS.

> *"…because I've got personal knowledge of MS, I think I've probably had more of an idea than most people would…" Elizabeth Employer*

However, acquiring knowledge through experiences can be detrimental, as individuals may develop false assumptions about MS, influenced by examples from their personal experiences. In some cases, employers may refute an employee's diagnosis of MS due to the mismatch with their own understanding of the condition.

> *"…unless you've got a family member with MS perhaps but a lot of people who visibly have MS tend to be visible because they've got a high level of disability and sometimes employers don't appreciate that, you know, that's not the case for everybody…" Hannah HCP*

Further, those who have had no experience of MS may lack any understanding of the condition. This affects not only employers, but HCPs who do not have specialist knowledge and members of the general public.

> *"I think unless Joe Bloggs or whatever, Joe Public, has had experience of MS people just don't understand it and don't really know and even healthcare professionals, a lot of people don't understand." Hayley HCP*

This lack of understanding can serve to make the lives of PwMS more challenging.

Theme 1: Knowledge Flow; Sub-theme: Routes to Knowledge; Sub-sub-theme: Signposting (meso)

Both subjective and objective types of knowledge can be shared between experienced parties. HCPs have the benefit of knowing how to access good quality information, even if they do not know the information first-hand; this can be done through either *signposting* or *intentional learning*. *Signposting* involves seeking out the specific knowledge of another individual, be it professional or experiential.

> *"I like to think most healthcare professionals would kind of, if they understand a person that's sat in front of them or a diagnosis, they would research and go to the right places and know where to ask the questions." Harriet HCP*

This is a useful skill, which could be beneficial in an employment setting too.

> *"I think people have been quite helpful when they've approached occupational health. They haven't always understood but, you know, they've always known organisations or people to contact or, you know, they've got more of that information." Hannah HCP*

Employer representatives describe how this process can work well to provide support to both the employee and the employer in managing work and MS.

> *"…the policy allows us to work through that with support from occupational health, with support from our in-house risk assessment, you know, workplace risk assessment people, we would also be signposted to outside organisations to help." Esther Employer*

The role of the HCP is to offer individualised guidance and advice, so that the PwMS can develop their own decisions. HCPs can offer support through guidance and advice. HCPs can share information of their knowledge but also signpost others to sources of information if they do not directly have the knowledge.

Although HCP knowledge could be limited, often they will actively seek this knowledge of their own accord, e.g., regarding legislation. Real life experiences may be one of the most useful learning tools. The HCPs approach seems to be patient led.

As well as specialist knowledge, experiential knowledge is also useful to share. This helps to edify communal exchanges and allows a network of support to develop. One HCP notes that although sharing knowledge is a good practice, this currently appears to be a one directional process. While HCPs might go to places of work to share their clinical knowledge of MS, it may be beneficial for employers to also approach HCPs to discuss their work-relevant experiences.

> *"So I never had a person from HR or from a senior person from management coming to talk about their challenges in dealing with patients like MS [...] so we go there and teach about MS but they should come and talk about their constraints, their challenges, as well." Howard HCP*

Theme 1: Knowledge Flow; Sub-theme: Routes to Knowledge; Sub-sub-theme: Intentional Learning (macro/meso)

Where *Signposting* involves seeking knowledge from an expert individual, *Intentional learning* incorporates accessing quality, critical knowledge via larger systems. The skills of intentional learning are usually developed in educational institutions or through professional training. However, these skills can later be transferred to methods of researching knowledge through other available resources. Intentional learning skills involve not only sourcing information from reliable sources but determining which information is likely good quality. Knowing how to find this type of knowledge is helpful in providing information to employers and PwMS.

> *"I'd probably just google it, yeah. And certainly in the charity there's the links to government websites and stuff..." Hayley HCP*

Having skills in intentional learning is also beneficial to individuals with MS and employers. This has certainly become easier and faster with technological advancements.

> *"...a few years ago you might have had to make an appointment with Citizen's Advice or your MS nurse or whatever else, whereas now you can kind of get most information at reliable websites, it's just knowing which reliable websites to look at or picking up the phone and actually speaking to somebody." Harriet HCP*

Being able to navigate relevant knowledge and information in order to support individuals with MS and their employers in managing work is especially useful when this can then be channelled appropriately to those that might benefit from the support.

> *"I've sent employers sort of like the MS Society stuff on, you know, what to do as an employer but then I know that the person that they're supporting suffers with fatigue, so I might send the fatigue management book from the MS*

> *Trust which is designed for patients but, you know, it's got, it might just help them to find it a little bit more relatable, even though it's not perfect" Hannah HCP*

Theme 1: Knowledge Flow; Sub-theme 3: Knowledge (In)congruence (meso)

Knowledge held by an individual, be it critical or experiential, may or may not correlate with another person or group. Managing knowledge incongruence is one of the challenges HCPs face in helping support employees with MS.

> *"...people don't understand MS, employers don't understand it and in fact I gave somebody some information yesterday about myths and misunderstandings about MS." Hayley HCP*

Harmonising the employer understanding with the individual's experience of having MS can present as a challenge when incongruous.

> *"…they think "ooh MS, lack of mobility, wheelchair, can't really speak, probably dribble a bit when they're eating" because that might be their perception of what people with MS are like. And obviously with the, you know, the vast majority of drugs that we've got, increasingly that is less and less the picture." Hannah HCP*

Due to the variability of how MS can manifest this inconsistent knowledge is not necessarily unexpected. It would be unreasonable to expect anyone to predict how MS affects any particular individual.

> *"I think one of the main challenges is people do not necessarily understand the illness. If you've not had any experience of the illness and it can present itself in, I mean obviously you'll know this, there are many different, well several different types of MS" Elizabeth Employer*

Thus, a key facilitator in successful work outcomes for PwMS may not lie in an increased understanding of MS, but a willingness to maintain an open dialogue about the unique experiences of each individual MS employee in their job role.

> *"…they had been in, you know, discussions with the manager, making the manager aware that they did have MS […] it was a case of something to be aware of, but let's maintain that open communication so that they felt comfortable being able to come to their manager and also to us, so that any support that was needed we could be there" Esther Employer*

Further, support systems that allow for an individualised approach may be more successful than 'generic' solutions.

> *"…it's easier in the sense that you can have that multi-way conversation, it's not just a piece of paper that you're getting after an appointment, you can actually ask questions, […], it's actually quite a useful way of trying to support somebody…" Esther Employer*

That said, there does need to be some level of understanding about the chronic, unpredictable nature of MS. Trying to pigeonhole PwMS into traditional illness perceptions is not useful.

> *"So I had, like, a couple of instances, got to fill in these very funny questionnaires, whether the patient can hold two kilos of weight for five minutes. How can I get two kilos of weight to get and then hold the patient in my clinic for five minutes? [...] and then asking specifically about what you think the patient will be like in two years' time or five years' time. Again, difficult to answer."*
> *Howard HCP*

Incongruence of knowledge is not just a challenge for employers in understanding MS, but patients with MS may misunderstand how the condition could affect them.

> *"...something that's come up for patients here is this, all these ideas around stem cell therapy and when the newspapers print, you know, miraculous cure for MS on the front page of The Sun or something like that, I think that that's been a big issue [...] printing knowingly false information or information that can just so easily be misinterpreted, it causes a massive amount of distress for people." Henry HCP*

Some of this can be due to media misrepresentation of information, or sensationalism. The perception of MS becomes skewed, and poor-quality information perpetuates false assumptions.

The lack of understanding about the impact of MS is partially due to the invisibility of the condition.

> *"...no matter how much you kind of tell them about a person with MS, they won't necessarily, not that they understand, but they might not have that empathy to under..., you know, to kind of understand how this can make a difference when somebody looks absolutely normal in front of them" Harriet HCP*

Invisible symptoms can present a mismatch between knowledge someone is being told versus their experiential knowledge using visual indicators. A common misconception of PwMS is that they are drunk, which can lead to stigmatisation and victimisation.

> *"By the end of the day the patient was so fatigued they were working with a broad-based gait, and the employers thought that she is drunk and there was a panel on her, and they asked me to comment on it." Howard HCP*

People may struggle to relate to symptoms which they cannot visually perceive or assess.

Discussion point; Fatigue

Fatigue is a major issue for PwMS but often not well understood due to how difficult it can be to quantify. This seems to be linked to the invisibility of fatigue that makes it difficult for those who have no personal experience of it to comprehend.

> *"...I think that's something that people struggle with all the time is the misconception that someone with MS is just a bit tired and why would they need specialist support or help within the workplace because they're just a bit tired*

> *because everybody just gets a bit tired so I think there's a real lack of understanding around that and I think people with MS, from my experience, feel quite embarrassed talking about that to their employers or to other people because they just don't have that underpinning knowledge that actually, for them, fatigue affects their mobility, their ability to concentrate, the cognition, the speech and all those things can have a huge impact on how someone can then perform their duties effectively within the workplace…" Holly HCP*

This can be frustrating for individuals with MS, who may feel that their chronic suffering is being invalidated or underestimated.

> *"… people will say "if one more person says oh yes I'm tired as well, it's not just you, I'm going to hit them because, you know, it's not the same kind of fatigue" and it's, you know, it's unrelated to whether you've had a good night's sleep" Hannah HCP*

Unfortunately, this lack of validation of fatigue as a debilitating symptom can lead to employees with MS feeling a burden of guilt which adds to their challenges of continuing work.

> *"…they feel a certain amount of responsibility because they're aware that the people around them just think they're tired and just being lazy, whereas, actually, they're absolutely exhausted, you know, that's the nature of fatigue, that they feel that they have to keep going because everybody else just thinks they're lazy…" Harriet HCP*

Theme 2: Structures of Support

Structures of support incorporates the systematic mechanisms within which those supporting PwMS to stay in work are operating. This includes structures on a macro level of society, such as *legislation. Legislation* in turn affects the *Specialist services* that are available across the UK. As well as these support services, *Finances* have a key role to play in how well individuals can access support. All three sub-themes have a bi-directional impact on one another, for example, financial aid may contribute to the services an individual is able to access.

Theme 2: Structures of Support; Sub-theme 1: Legislation (macro)

Legislation is affective at a macro-scale, within the UK or even at international level (e.g., Declaration on Fundamental Principles and Rights at Work, 1998).

Legislative policy prevents employers from negatively discriminating against employees who may be disadvantaged due to a disability. This includes a diagnosis of MS. One HCP notes the importance of such legislation in providing PwMS equal opportunities in the workplace, despite the challenges of creating this legislation.

> *"…if we're employing somebody and they have a disability you have to give them a level playing field, you know, they're not starting at the same point as everybody else, they've got a huge hill to walk up before they even walk in that office door in the morning … and then you're being expected to perform like*

> *everybody else, you know, that's a very difficult thing to get across in terms of legislation…" Hannah HCP*

Relevant legislation is a helpful support mechanism for employees with MS if they do face unfair working conditions. However, legislation does not prevent issues of discrimination occurring. Employees can still find themselves in a position of having to defend their rights in the workplace, which adds further burden to managing their MS alongside work.

> *"…a very young manager had come in and was obviously inexperienced in management and felt that the way to go in was to come in and throw their weight around so they undid all the measures that had been put in place and my patient said, "he can't do that, that's actually illegal" and that went very, very high within the organisation. It turned out that the manager had to back down…" Hannah HCP*

In addition to legislation, there are government schemes in place to aid employment opportunities for people with disabilities. Although not a legally binding process, employers who sign up to the Disability Confident Scheme (previously Guaranteed Interview Scheme) make it a policy to offer a guaranteed interview to anyone with a disability, provided they meet the minimum criteria to a role.

> *"When we recruit to post, our application form does ask if the individual has a disability. The reason we ask that is in order that if they meet the essential criteria they are guaranteed an interview so, and at interview we would ask them if they needed additional support" Elizabeth Employer*

Despite UK legislations and schemes which protect employees from disability-related discrimination, PwMS fear losing their job or facing barriers to career progression if they disclose their condition. In these circumstances, HCPs discuss how a strategic disclosure can ensure protections are upheld.

> *"I said to her. "You don't know. You don't need to go and tell your boss, but speak to occupational health and then maybe involve line manager at some point if you're really worried about losing your job,"" Howard HCP*

Such strategies are helpful in empowering PwMS to prevent unnecessary barriers.

> *"I think there's something isn't there about if you frame certain problems in terms of being related to the condition, you're protected by certain rights that you might not be otherwise" Henry HCP*

Healthcare professionals may be well-placed to provide support for PwMS who are trying to navigate their legal rights at work.

> *"…. I was just thinking of a guy recently I saw who said, I've had enough, I'm walking out! I think it was a bit of a knee-jerk reaction and I was like what's going on, you know, they're threatening to discipline me over too much sick leave and they don't understand that I've had relapses, that I've been adjusting to*

> *disease modifying treatments and I said, okay, come and see me, which we did within a week and then the day I saw him we talked about it, we wrote a letter to his manager explaining everything and he then contacted me the next week and said, thank you so much, that's really helped, it's kind of cleared the air, I'm getting more support." Hilary HCP*

Thus, having access to specialist services, including different healthcare professionals can be valuable to successful employment outcomes for employees with MS.

Theme 2: Structures of Support; Sub-theme 2: Specialist Services (meso/macro)

Specialist services includes healthcare services and employment services available to PwMS. This can be extremely varied across the UK as well as across different organisations.

> *"So it does kind of come back to this issue of like postcode lottery I think, you know, people in different areas of the country will have massively variable, yeah, access to services…" Henry HCP*

Notwithstanding the variance across different parts of the UK, there is a growing UK-wide strain on these services, which may be negatively impacting the support that HCPs can offer.

> *"Also psychologically trying to make sure that they've, if they are struggling with their diagnosis or low self-esteem or low-grade depression or whatever, because of it, that that is being adequately addressed through counselling services that we have available to us, medication if necessary. But obviously we're slightly limited by the, the sort of limitations of what is available on the NHS in terms of psychological therapy." Hugo HCP*

One HCP details how an increased availability of these support services could directly impact outcomes for PwMS.

> *"…the way that we diagnose is improving, so more people are getting diagnosed, and then at the other end of the spectrum people are living longer, so people are living longer with MS. So obviously our caseload has gone up which doesn't, you know, we're not allowed to do home visits, we're not commissioned to do those anymore, we can't do workplace visits, which is a real shame because, you know, I think with a bit of passion from myself or my colleague we could get in there and say, you know "they're not just tired, this is what it is, this is how they need support…"," Hannah HCP*

Employment services available in the workplace are generally more varied across different organisations. However, as will be discussed later, some workplace cultures are geared closer to employee wellbeing through their services, as demonstrated by Esther's account.

> *"So [staff guidance document] references Access to Work, also references our occupational health department and the counselling service, we've also got childcare and career support services […] it talks about mental health resources, so Rethink.org, Mind.org.uk and then shift.org.uk and then mentalhealth.org.uk.*

> *Our occupational health are usually very good as well at signposting individuals to other sources of help outside of the organisation" Esther Employer*

Commonplace employment services, such as occupational health advisors, can be beneficial both to employees and MS and their managers who may need to seek advice on how best to support their staff.

> *"...we look at ways we can support them, you know, through advice from occupational health, the occupational health physicians, or sometimes from our health and safety advisers, or as I say Access to Work as well." Elizabeth Employer*

Theme 2: Structures of Support; Sub-theme 3: Finances (micro/macro)

Financial security is important in a Capitalist system; PwMS may require financial support services if they need to reduce their level of work participation (e.g., reducing hours, or even leaving work).

> *"...from a financial point of view they need to work and we need to support them within that, particularly at the moment there's been a lot of anxiety around PIP and I think financial, and, you know, the economy generally." Hannah HCP*

Supporting someone with MS to stay in work may be dependent on finances. Employers might require finances to purchase suitable equipment and make adjustments.

> *"I suppose another thing Government might be able to help is supporting employers with a little bit of financial to make adaptations as needed...in some areas, at some point, there were grants and such, but I'm not sure there would be now, you know, whether that's available or not." Harriet HCP*

Recent changes to the welfare system has seen schemes such as the Personal Independence Payments (PIP; previously Disability Living Allowance) enforce stricter criteria and more stringent assessments. This creates additional uncertainty for PwMS who cannot rely on financial aid from the state, should they need it.

> *"...going back to what I was saying before about Personal Independence Payments and the ease with which people can claim benefits, it just seems like it's got harder and harder and harder and I think that's awful. You know, if you think about people with, people who really need those things, the fact the process has got more and more difficult is just like, oh it's just sickening really, it just makes me upset. Yeah, if people have genuine cognitive problems and they're expected to fill out forms that might be tens and tens of pages long that you can fall down at any hurdle, I think that's really unhelpful" Henry HCP*

Whilst the UK currently has a welfare system in place which was originally intended to support people who experience barriers to financial security, these additional hurdles are making this support difficult to access.

> *"So when there are more job losses, when they are struggling to get the PIP payments and all that they struggle and they will have to go back to work but they can't…. Sometimes they ask, "I can't do any job but I am not getting any PIP payments what should I do?" and as a clinician you are stuck … more and more I'm getting these calls, or my secretary is getting calls or our nurses, about letters to PIP people to say that they want a letter from me supporting their payments. …because more and more PIP applications are being turned down if they perceive that the physical aspect of the MS is okay." Howard HCP*

Not only are PwMS struggling to access financial support, but some who have previously received it are now having it removed.

> *"I know that people, there's been, you know, there's been an overhaul hasn't there … I had a lot of phone calls from patients who said that "they've taken [PIP] off me and what am I supposed to do?" And, you know, people were pretty devastated understandably…" Henry HCP*

This financial insecurity can add to the negative psychological impact for PwMS already experience work instability.

> *"…if they lose their job and they lose their wage or, you know, for whatever reason, they give up their job and they give up that wage, unless they've got the finances there it's a massive adaptation to kind of even move forward or move into unpaid employment" Harriet HCP*

Theme 3: Capacity for Support

The capacity of an organisation to support an individual with MS centres around two key sub-themes: *Organisational culture* and *Organisational practicalities*. When those with power in an organisation foster a supportive, pro-diverse workplace setting, this can have positive repercussions which filter down to each individual.

An employment role which can be easily adjusted to suit an individual with different abilities or needs is inevitably more secure to retain. Some work adjustments may be impractical or even impossible; for example, an individual with gross motor deterioration could not practically continue a role which requires extensive manual labour. However, what might seem unfeasible may simply be an absence of lateral thinking. With advances in technology, adjustments are becoming more practical and affordable.

Organisational culture inherently impacts *Organisational practicalities*, in that an openness to diversity will determine how an employer is willing to manage the needs of the organisation and its personnel. Thus, organisational culture is important to the success of work retention.

Theme 3: Capacity for Support; Sub-theme 1: Organisational Culture (macro)

Organisational culture is a multifaceted paradigm. On a macro level, the culture of work in the UK creates a backdrop for how organisations and individuals regard work.

> *"…I think we're more and more working in a culture where people don't take breaks and, you know, you or I might get by on that but somebody with MS that could be the difference..." Hannah HCP*

In Chapter 4, the concept of the *'Ideal' worker* was discussed. Elements of this concept are also noted during HCP interviews. This draws parallels to the current UK culture of work, in which illness is stigmatised.

> *"...people are afraid to be off work poorly, even those I think who don't have MS. Because there's no leeway anymore and people are afraid to… I think they're afraid to lose their job" Hayley HCP*

Embedded in Capitalist ideologies, work culture in the UK is consonant with busyness and *quantity* of output. This can be challenging for PwMS, who may have specialist skills, but have difficulty maintaining a fast paced or onerous method of working.

> *"…I think they've got their targets, they've got to meet all the criteria as managers, to tick whatever boxes, and it's like it doesn't fit in neatly, MS, at all to any of these… it's like a round pin in a square hole, isn't it?" Hayley HCP*

The concept that employees should be filling all their available time actively working may not be conducive to effective work. Contrastingly, employees who take rest intervals risk being seen as idle in their work ethic.

HCPs in particular discussed how PwMS may experience work differently as a result of the sector type and organisational size. It was generally seen that private sector employment offered less flexibility, security or understanding around different working needs. Howard describes how a private sector employee with MS was denied a permanent position, where their non-MS co-worker equivalent was offered a more secure contract. Henry also notes that private sector work appears to prioritise productivity.

> *"…I get an inkling that there's a massive drive in private sector on productivity and getting the most out of your employers in a way that maybe there isn't in the public sector, traditionally anyway." Henry HCP*

These different priorities between private and public sector type work appear to be demonstrated in the employer representative interviews. Elizabeth notes how her public sector organisation embraces an overall priority toward employee wellbeing.

> *"We do have a health and wellbeing project going on at the moment and we do encourage people to take up new skills, new exercises, new games, you know, that sort of thing, but it's for all staff, not just for the people with disabilities or with MS." Elizabeth Employer*

HCPs also considered differences by organisational size and certain organisational fields. However, these responses showed greater variability; where Howard noted that the NHS is often a very good employer for workers with disabilities, Hilary had a different experience.

> *"… some employers get straight in touch and say, oh that would be brilliant, please can you come and have a meeting with us and occupational health, we're really struggling, we don't know how to support this person, we don't know enough about MS, please come and educate us […] and so often bigger employers, I would say are better. Royal Mail's another one. NHS isn't so good, sadly, in my experience. Again, not sure why that is." Hilary HCP*

Similarly, while some HCPs noted that larger employers could be better due to increased resources for support, Hannah points out that smaller organisations may have stronger interpersonal working relationships with their employees, affecting their motivations to support them.

> *"…if it's a small organisation they're more likely to know the employee personally, they're more likely to be able, in a position to see their performance day-to-day […] and managing this person on a personal level rather than just a faceless employee…" Hannah HCP*

Hannah also identifies how an organisation can have many good policies, but successful implementation of these is dependent on the attitudes of the persons responsible for enforcing them.

Another key theme identified in Chapter 4 is that of *Togetherness*, which addresses the level of mutual trust between an employee and their manager or organisation. Professionals also highlight the role a sense of trust and understanding hold in employment experiences of PwMS.

> *"And there's a lot of suspicion I think as to like whether occ[upational] health departments and the assessors are tools of the management or whether they are really independent and have the patient's interest at heart, and I think people do just have different experiences of that." Henry HCP*

Interestingly, Henry considers "*tools of the management*" as contradictory to "*have the patient's interest at heart*". Having positive interpersonal trust and respect seem to be key factors in the relative experience of an employee with MS.

> *"So the people that seem to do better are the ones that have the supportive employers that will make as many adjustments as possible, even if it's coming in later in the day or, you know, having a break through the day. I think, often if there seems to be a clash, even if it's on a more personal level; that can make life difficult." Harriet HCP*

Work colleagues may serve as psychological support networks to individuals with MS, whereas the employer may have a more functional support role. Awareness is a form of support, by proxy. In being aware of an MS diagnosis, employers can verify their willingness provide additional support for employees, should this be required.

> *"…it's not even about somebody having MS, it's about being a supportive colleague and recognising that, you know, you might just need to be aware of something in case they need a hand with something…" Esther Employer*

This sentiment is reflected by both Employers and HCPs. Harriet notes that these positive interpersonal relationships are likely to be stronger over time, thus employees who have worked with an organisation for a longer period are more likely to be supported to keep working. This is sense of loyalty appears to counteract potential practical barriers, such as organisational size and financial power.

> *"I've had people work in fairly big organisations, fairly big like banking organisations and they've been brilliant and they've put in so much support and assistance to keep that person in work and in those kind of environments you see people with really quite severe disabilities that are still able to pin down part-time, full-time employment and then you can see other people where their employers are just so unhelpful, don't want to know, see it as a big problem and those kind of employers can push people out of employment that have got the most minimal disability that you just think why, you know, the smallest amount of tweaking or insight into the problems and that person would have been able to do the job just fine." Holly HCP*

Theme 3: Capacity for Support; Sub-theme 2: Organisational Practicalities (meso)

Organisational practicalities can differ depending on the size, sector and relative culture of an organisation. Adaptations may be more feasible due to the size of an organisation, owing to their relative financial capabilities.

> *"… I was working with two people with MS at the same time, similar kind of levels of disability, both used either wheelchairs or kind of walking aids, cognitively they were fine, there weren't any major problems but they just had massively different experiences and the woman who worked in a big bank could quickly, well the employers could quickly implement meaningful adjustments that the small employer couldn't or found it difficult to, you know." Henry HCP*

Despite legislation requiring organisations to make workplaces accessible, this was not enforced if the organisation was unable to afford alterations. Although it may not be reasonable to expect a company to face financial hardship as a result of legislative change, this sustains barriers to work for people with mobility limitations.

> *"…for people with wheelchairs, it was expected that places and companies that could afford to adjust their outside would get ramps, etc, and wider doors, if they could afford it, if they could not afford it then they didn't have to do it" Harriet HCP*

Another impact of organisational size on the capacity of an organisation to support an employee with MS may be due to personnel. For example, larger organisations with a dedicated department for occupational health or HR will have the benefit of a support team with 'in-house' knowledge about the workplace as well as legislative and other practical knowledge.

> *"…it depends again on the organisation. How big and how small it is. […] sometimes they don't have an in-house person so they kind of ask a third party, and that's when it kind of gets a bit more complicated." Howard HCP*

Type of work has a role to play in workplace experiences for PwMS. These difficulties are tied in with challenges across the workforce, due to increased demand on services. Public sector work faces inadequate funding and increased pressure to do more work with less resource.

> *"…their funding is static and yet their caseload is growing, so their office environment is very much centred around doing more and more for less and less and obviously that directly impacts on the workforce. So, you know, the environment becomes more stressful." Hannah HCP*

This is challenging for all employees, but can be a tipping point when managing this alongside symptoms of MS. The disparity between different organisations is evident in the following account one HCP recalls of a patient who changed to a more accommodating organisation.

> *"…she was the lady who's moved to a new job and she said, "I cannot believe the difference in the way I am now being… it's okay, it's okay to come in a bit later because we know you're struggling in the morning." To how it actually impacted on her previous job, how it was just so rigid really. So, I mean in terms of, yeah, stress and anxiety levels are through the roof with people who are really struggling, but trying to continue in that work role, and then that impacts on their MS symptoms" Hayley HCP*

A work culture grounded in flexibility and acceptance can have a dramatic impact on work experiences and outcomes, despite not needing to make expensive alterations or alter productivity levels. On the other hand, some organisations can make every effort to be accommodating, but very will be a limit to how much a role can be adapted.

> *"…there was a lady in our department who was unable to continue in the role because you couldn't make, you couldn't adapt the role enough for her to continue in it, do you see what I mean? It depends on the role, whether or not you can make those adjustments…" Elizabeth Employer*

In these situations, organisations may offer redeployment to an alternative role. This is often a route available in public sector work and offers a solution to having to leave the organisation entirely.

> *"…with any adjustment there is always the risk that we can't necessarily make, it's not a reasonable adjustment, you know, there's always a risk that we may need to look at an alternative role for somebody" Esther Employer*

It may be easier to facilitate adaptations to a role when the employer can identify transferrable skills in the employee. Although practical, organisational culture can affect how effectively this is achieved.

> *"…so this individual is very adaptable and they have a lot of skills and experience that the theatre management team recognise and value. So to work in theatres you don't necessarily need to be at the bedside in the actual theatre with the patient who's being operated on, there are a number of roles within theatres to support the environment and the management of theatres and the process and the coordination, and, which also means that adaptations could be made so they could still work in the theatre environment using a wheelchair…" Esther Employer*

However, even where an organisation has a culture of acceptance, when MS symptoms have implications for the safety and wellbeing of others, this may have to mean leaving that role for the benefit of a wider community.

> *"… so he came to the point where he through the assessment and through discussing it in terms of his kind of rehab strategies it would be around not taking on jobs that were perhaps more risky or if he were to get things wrong would have absolute dire consequences, you know, so that, it was quite important really, which, you know, that might differ from somebody with a different kind of role, somebody that didn't maybe bear the same responsibility" Henry HCP*

Theme 4: (Three-legged) Responsibility Stool

The three-legged stool has been used frequently as a literary metaphor for the requirement of three equal sources of support to create a stable outcome. The earliest documented reference to this metaphor is from Reinhard A. Hohaus in 1949, in an address about the Social security programme in the US (DeWitt, 1996). Three legs are the minimum that a stool needs to stand unaided. The concept goes even further, in that the three legs that a stool stands on fulfil the mathematical formula by which 3 non-collinear (i.e., not on the same line) points are needed to define a plane in three-dimensional space. However, if the stool were to have four legs, this creates multiple 3-point planes on which the legs can 'wobble' between, thus is less certain to be stable.

Generally, professionals felt that the responsibility of managing employment with MS is shared, at least between the employee and employer. It is important to note that the question of responsibility was incorporated into the interview guide, and thus responsibility itself as a theme did not occur. However, the realisation that responsibility did not lie in a sole party but rather was a process of partnership and open communication featured strongly in these interviews.

Specifically, employers recognised their duties in supporting employees, but that this required cooperation from the individual with MS. HCPs felt that they had responsibility in sharing their knowledge to help guide positive work outcomes, but that the employer and employee with MS must work together effectively.

Theme 4: (Three-legged) Responsibility Stool; Sub-theme 1: The Individual with MS (micro)

Continuing work and disclosing MS are both personal decisions. As such, it is the responsibility, in the first instance, of the individual what they choose to disclose to their employer. If an individual with MS needs support, they need to communicate this.

> *"I think it's a partnership [...] if the person with MS wants to continue work, we will continue to support them. If they don't want to continue working then that's, you know, up to them." Harriet HCP*

However, the individual also has a responsibility to acknowledge and seek support for any negative impact their MS is having on their wellbeing and ability to conduct their work safely. MS is a hugely individualistic condition; thus, the individual with MS is often best placed to explain how their condition impacts their work. As such, there is an onus on the individual to seek support should they need it. Further to this, Hugo notes that disclosing MS to employers before problems arise can be a means of managing interpersonal relationships.

> *"I think employers are more likely to be sympathetic and on side if they're given early warning that there may be problems ahead." Hugo HCP*

Letting others know if and when they need support is key to overcoming workplace barriers for PwMS. It also helps those who are trying to support the individual, by allowing them to prepare and plan any accommodations.

> *"I think if people do let you know at least you can prepare in advance for what they might need." Elizabeth Employer*

Further, by maintaining an open dialogue with employers, employees with MS help the employer to understand their needs better and reduce unnecessary burden.

> *"…it helps employers understand that if, you know, there's too much pressure on people to go back too early when they're not still feeling particularly great, they're only going to go off sick again" Hannah HCP*

Although the responsibility to communicate with employers and HCPs was discussed, ultimately, the professional group recognised that individuals with MS have a primary responsibility to themselves in terms of maintaining wellbeing.

> *"So I think there is something about that kind of willingness to face the realities of what's actually going on for them, you know, physically, emotionally, cognitively, in relation to their work and productivity and sense of fulfilment at work". Henry HCP*

Theme 4: (Three-legged) Responsibility Stool; Sub-theme 2: The Employer (meso)

Employers have a duty of care to their employees, whatever their condition or state is. In addition to the importance of individuals with MS communicating with their employers, the responsibility of employers is best upheld by maintaining continued engagement with the individual to ensure their needs are being appropriately met. Employers can help to reduce anxiety and uncertainty by being proactive about support options; this may mean having potential solutions or other roles ready rather than dealing each problem as it arises.

> *"But first and foremost it's always about working with that individual and trying to see what we can do to support them to stay, A, in the job that they're doing or, B, is there an alternative role that they can do that allows further adjustment to be made." Esther Employer*

As well as social notions of responsibility, the employer does have a legal responsibility to support individuals with disabilities in the workplace. Disability rights embrace equal opportunities rather than notions of productivity underlying capitalist systems.

> *"…it is the openness with management or your line managers and their level of understanding, I think that, and willingness and almost kind of, you know, a wish to keep this person in the position for as long as they can and with the knowledge that they might, you know, the productivity or output might be different to the next person but that's fair, that's what it is, that's what it means to adhere to disability rights sometimes…" Henry HCP*

Whilst there is a legal onus on employers to make reasonable adjustments in the workplace for PwMS, Hilary points out the challenges of the meaning of "reasonable" in making adjustments.

> *"Yeah, well I have had a situation with an individual where his employer was very, very good and they made change after change after change and […] he was at a point where he just couldn't do the job anymore and he didn't want to admit that but his employer was saying, we can't make any more change, it's not financially viable now. And that was a helpful way of measuring it because I said look, you have made reasonable adjustments, you've been very reasonable and now it is about me and you as an employer, helping this individual understand that he's probably not able to do the job and they looked at redeploying him in to a different role and I said, well that's great, you know, he's still got a job but it was understanding that they'd gone beyond what was reasonable." Hilary HCP*

Hilary goes on to discuss a situation in which safety concerns had become an issue for an employee with MS in the workplace; employers may have to balance decisions regarding reducing barriers to work but also ensuring the safety of their employees.

Theme 4: (Three-legged) Responsibility Stool; Sub-theme 3: The HCP (macro)

The responsibility of the HCP falls to ensuring the individual with MS has access to key information and support as well as mediating employer relations.

> *"But then yeah of course as the MS MDT, we also have responsibility to make sure that patients are accessing or have accessed all the support they might need" Henry HCP*

HCPs will have knowledge of what constitutes normal adjustment, versus what might be chronic or debilitating. Although one HCP felt that providing care to patients in health-related concerns was not appropriate to employment, as distinct life domains, the majority considers that HCPs, employers and PwMS can work together, providing their relevant expertise to the overall context of managing MS at work. Howard points out that employment outcomes are more likely successful when the interaction and communication is fluid between employer, PwMS and HCP. The HCP can use their knowledge to explain things that the individual with MS or employer may not be aware of in MS.

> *"So I think it's three-pronged. A patient should be aware that there are a few things which can be physical, like, for example a new diagnosis, and number two, as a clinician I should try and explore a bit as well, so that is my responsibility as well. Third is employers, sometimes they don't understand the nitty-gritty of the disease itself so the general perception about a person with MS is something about physical disability, not about psychological or the fatigue part of it, so I think so the answer is maybe all three of us has a role in equal proportions" Howard HCP*

Not only do HCPs have specialist knowledge that they can share to help inform PwMS and employers, but due to this knowledge, HCPs are seen to have a voice of authority. This can provide useful validation to an employee seeking support for their adjustment needs.

> *"I think there's a huge role for health professionals and probably we should be doing more or be facilitated to do more than what we are because actually the MS nurses, the MS physios are probably in prime place, we've got a good understanding of the condition, we've got a good understanding of the fluctuations and the problems it could be and we can advise a patient all we like but it's not the patient that really needs advising it's the employee... Employer even, not employee, employer." Holly HCP*

In the Professionals group, it was primarily the HCPs who indicated their responsibility as a wider group, while the Employer subgroup made mention to specific specialists such as Occupational Health advisors.

> *"I just see it as part of everything that I do really, I don't see that as a separate thing at all because it's just part of what I do really. When I'm assessing them I don't necessarily say, "Is everything okay at work?" But I usually sort of just open up with, "And how have you been?" And leave it open like that really. But a lot of the time work does come into it" Hayley HCP*

This notion of work as a component of overall health and wellbeing supports the final and foundational theme of MS and work as a part of the *Life Journey*.

Theme 5: Life Journey

The *Life Journey* makes up the foundations on which all other themes rest. In that, all socially or internally constructed mechanisms involved in work and MS contribute to the overarching experience of living.

In the particular context of managing barriers and facilitators of MS and work, three prominent sub-themes occur: *Meaningful engagement, The MS journey and Non-MS barriers.*

This is somewhat inevitable, being that each sub-theme fits an element of the overall research topic. *Meaningful engagement* encompasses employment as a meaningful and valued activity in UK society. *The MS journey* is a fundamental aspect to managing MS across many aspects of the *Life journey*, including work. And reasonably, there will be additional barriers not related to MS when continuing work, as people are far more complex than a singular diagnosis.

Theme 5: Life Journey; Sub-theme 1: The MS Journey (meso)

MS is a spectrum and can mean a multitude of different things. This can make a disclosure of MS difficult for employers to comprehend and complex for individuals and employers to navigate in the work setting.

> *"I've got some MS patients who've had MS for a decade or more and are still reasonably well and for them it's no problem. But others, obviously, it's fairly rapidly progressive for some of them and that's just not realistic, yeah" Hugo HCP*

Further, individuals could be at varying stages of their MS journey. Diagnosis of MS can be an overwhelming time, with lots of new information to take on board, making additional information difficult to process. Employment considerations need to take into account where someone is with their MS journey. People at earlier stages or with less severe progression of MS may not even identify as disabled, and this label has meaningful consequences for how they engage with their employment.

> *"… obviously an enormous amount of variation and massive, massive amount of difference and uncertainty and with the disease progression, the kind of course you might expect, but if somebody's just been diagnosed they might not identify as having a disability and I think that's a really important thing, particularly in relation to employers because of course, yeah, opens lots of avenues and doors that wouldn't be there without that kind of label so to speak. I know there's massive issues around that and what disability means to people" Henry HCP*

Labels such as "MS" or "disabled" appear to play a key role in accessing appropriate support for employees. One HCP describes a spectrum of conditions related to MS which are not accounted for under employment policies, but for which individuals may require as much, if not more, support.

> *"…but people don't understand when I say optic neuritis or a myelitis, which is a part of the spectrum […] I think that's a group where they don't get*

> *more help because, "Oh, you've not got MS so we can't give you…" if it's a myelitis you know they don't understand that part although the symptoms are worse off in myelitis patients, who can't really walk…" Howard HCP*

A notable symptom of MS is fatigue, which is not well understood by those who do not experience it.

> *"it's an invisible symptom often that people cannot understand, employers or colleagues might think "oh fatigue, yeah, I know what it's like to be tired" but it's not being tired, it's a massively debilitating symptom that doesn't improve with rest and really has a great impact on what's possible day-to-day and that idea of a kind of a battery that drains and then it is empty and needs to be recharged" Henry HCP,*

Unlike acute cases of illness, which end with recovery, MS follows a trajectory of periods of deterioration followed (in some but not all types) by stages of remission, which are uncertain and indefinite. Thus, MS is a lifelong journey to which the individual will need to continually adjust.

> *"…it's like but you're having this treatment forever, while ever you're eligible to have it and the reason you are at work is because you're having this treatment, because it's keeping the relapses at bay and it's doing good for you" Hayley HCP*

Theme: Life Journey; Sub-theme 2: Meaningful Engagement (macro)

Employment is important for providing meaningful activity, sense of self-worth and a healthy routine for individuals. Professionals note the importance of working as providing purpose and normality.

> *"…if I had the Maslow's hierarchy of needs, we might be able to discuss it from there, but, you know, it kind of, it gives them a sense of self, sense of achievement, which means that then they're providing for family, that, you know, support, so it gives them a sense of who they are in their home environment. So it has an extensive personal effect, you know, not just in work, but outside of work and everyday life." Harriet HCP*

This sense of self that work links in to is grounded in societal norms of paid work as a form of achieving social value. Howard points out the high priority of employment in Western culture. This may be different in cultures outside of the UK, or even the western first world. Hilary also notes how paid work provides value and purpose.

> *"…gives that sense of worth as well really, still have value, still have a role to play and I think for a lot of people when they leave that is one of the biggest challenges, I think, is that loss of role, that sense of purpose." Hilary HCP*

Employment is a core aspect of identity in western countries, and especially in the UK which functions under Capitalist ideals. Retaining meaningful employment may be about preserving an identity, particularly following a diagnosis of MS which can have a dramatic impact on sense of self.

> *"…for so many of us, all of us, you know, our work is a part of our identity isn't it, you know? If you write on the back of a bit of paper, you know, five things that describe who you are, it's likely one of those is going to relate to what you do or what you, for a lot of people what they've trained in or what their job is or their job title or the industry that they work in…" Henry HCP*

Staying in work can mean keeping some level of normality and familiarity amidst the uncertainty of MS. Chronic illness and disability can be riddled with negative stigmatisation and feelings of lower social worth within a society that perhaps subconsciously favours the able bodied.

> *"if we can keep you in a relatively normal environment for you for as long as possible I think that's really valuable as well emotionally, you know, people feel that they're still contributing, they're still a valid part of the workforce, they're still a valid part of society, so I think that's key as well." Hannah HCP*

When employers can recognise the value of supporting an individual to continue working in a meaningful way, this has a significant positive impact.

> *"…we want individuals to feel that they are making a contribution, and I think that's just as important." Esther Employer*

Theme 5: Life Journey; Sub-theme 3: Non-MS Barriers (meso)

As well as MS existing on a spectrum, people are a spectrum of whom different backgrounds and personalities may contribute. Coping mechanisms play an important role in how employees manage and respond to workplace barriers.

> *"MS is a spectrum. A person is a spectrum as well. Their personality and their disability, how they cope with their disability is again different. There are people who are really disabled but they are well-motivated and they can carry on." Howard HCP*

Individual differences contribute to how an individual with MS approaches their work and manages their condition. This, combined with level of support from an employer, can make leaving work a more likely outcome for PwMS.

> *"...you could have someone with a quite mild disability and really unsupportive boss and not that motivated really to work either, then they're not going to work." Holly HCP*

PwMS are at increased risk of mental health issues such as depression or anxiety (Feinstein, Magalhaes, Richard, Audet, & Moore, 2014) however these difficulties may be irrespective of an MS diagnosis. One HCP discussed an incident in which a patient had experienced significant trauma.

> *"…it would have been false and it would have been unhelpful to attribute those problems of hers to MS." Henry HCP*

Being able to dissociate these difficulties from MS in order to support the individual appropriately is important. There is a risk with MS that difficulties are automatically assigned to the condition, and this can serve to invalidate other challenges that present themselves. Not only can individuals face a variety of challenges, but employees may also be in a harmful workplace environment.

Discussion

This study seeks to learn from PwMS, relevant health professionals and employers about working together to facilitate job retention in MS. The research also aims to understand what this combined wisdom might indicate with regard to the *forms* any interventions might take. Specifically, this subset of the study seeks to understand the broader limitations and facilitators in place to maintaining work for PwMS in the context of national and local policies, as well as to gain knowledge of the experiences of health professionals in this area.

To achieve this, the objectives were to interview 6-8 relevant health professionals and a further 6-8 employer representatives to understand what helps and hinders job retention in MS and, along with relevant policy documents, understand the wider context surrounding employment and MS to create a picture regarding where best to target interventions and what these interventions should be. In total 8 health professionals were interviewed, covering a range of different specialities relevant to the healthcare management of PwMS. Further details are given in the Methodology chapter. Unfortunately, the difficulty recruiting employer representatives meant that only two people from this group were interviewed.

Five key themes were identified via critical grounded theory analysis: *Knowledge flow, Structures of support, Capacity for support, (Three-legged) responsibility stool* and *Life journey*. These themes encompass not only potential physical barriers and facilitators to people working with MS, but metaphysical and social structures which may have a very real impact. Each is discussed in the following with respect to the extant literature and theory.

Theme 1: Knowledge Flow

The theme of *Knowledge flow* sets the scene for all experiences related to work and MS. What knowledge is held, by whom, to what extent, and how this knowledge is shared are all important factors to how PwMS define themselves and are defined by others. Knowledge is an activity of categorisation; to put information in some kind of order allows humans to understand it, interpret and share it. By this means, knowledge is a result of our experiences but also gives shape to them.

Through the interviews with professionals, it became apparent how different types of knowledge can play different roles in people’s experiences and understanding of MS at work. For example, *Internal knowledge*, which is generally subjective, is prioritised by individuals when forming their assumptions and building a world view. Objective, critical knowledge on the other hand is regarded as good quality and valid but must be actively accessed rather than automatically. Although public knowledge can be based on subjective or objective nuances, this has the greatest power to affect cultural changes. This is because public knowledge is widely shared and has the greatest potential for visibility. Visibility and MS are explored later in this discussion.

De Jong and Ferguson-Hessler (1996) argue that, while knowledge can be categorised into many types, it is more meaningful to determine knowledge in the context of its function. Knowledge has different types but also different qualities, for example, superficial vs deep. Knowledge schema can be structured using superficial knowledge, which may lead to false assumptions or interpretations. This may explain how someone with limited experience of MS draws false conclusions based on a superficial understanding of "disability". Understanding how knowledge types and qualities interrelate can be useful for educators in conveying meaningful and lasting education for employers of PwMS.

De Long and Fahey (2000) define knowledge as "*a product of human reflection and experience*" (p.114) and perceive that knowledge can exist at individual (human knowledge), group (social knowledge) or organizational (structured knowledge) levels. They posit that knowledge is crucial for decision making and explore how organisational culture is intrinsically linked with how knowledge is shared, used, and prioritised within that organisation. These three levels of knowledge are not dissimilar from this analysis, with internal knowledge being parallel to human knowledge, critical knowledge as structured knowledge and public knowledge as social knowledge.

Knowledge can be subjective or objective; neither holds less validity necessarily, but how this knowledge is recognised and treated may be important to how managing MS in the context of paid employment is experienced. This is further explored in the context of the three types of knowledge identified in this analysis: internal (subjective), critical (objective) and public (mixed) knowledge.

The Leventhal, Phillips, and Burns (2016) common sense model of illness shows how people perceive and find strategies to manage their own illness experiences. This model itself shows the expected trajectory of illness, which is generally linear in form. People who have experienced this "classic trajectory" of illness may try to apply their own experiences to that of MS. However, MS does not follow a "normal" illness trajectory. This study further supplements literature which deals with issues surrounding the invisibility of MS. Invisibility can create challenges regarding validation as well as place responsibility on the individual to make decisions around disclosure (Norstedt, 2019; Valeras, 2010).

Reed, Meade, Jarnecke, Rumrill, and Krause (2017) drew comparisons between disclosure decisions of PwMS and the Integrated Behavioural Model (IBM). The IBM proposes that behavioural intention is governed by factors of societal norms, perceived power and personal attitudes or knowledge (Fishbein, Hennessy, Yzer, & Douglas, 2003). MS does not often fit to the social narrative of “disability” or the commonly accepted trajectory of illness, thus individuals with MS who disclose risk being ostracised by their work peers.

Bradley A. Areheart (2008) consider the “goldilocks dilemma” of disability as a result of American Disability Act (ADA) schemes, by which individuals find themselves being judged as either “too disabled” or “not disabled enough”. A similar situation seems to occur here in the UK, not only with the welfare systems such as Personal Independence Payments (PIP), but in a socio-organisational context; one participant talked about how much easier it is to understand that a wheelchair user justifies workplace adaptations in comparison with an individual with no visual mobility challenges; “Not disabled enough”. Then, another talks about the perception on the other extreme, whereby the individual in a wheelchair is deemed incapable; “Too disabled”.

One participant spoke of the difference between objective medical knowledge of how a person’s condition is impacting them by contrast with their personal subjective experience. The concept that subjective knowledge may impact an individual’s experience greater than objective knowledge is supported by a study by Wilski and Tasiemski (2016) in which they evidence that personal factors and illness perceptions are more influential than objective measures of disease impact. Critical knowledge is sometimes perceived as more valid due to positivist verification and the ability to repeat and relay acute information; however, this current study, as well as Wilski and Tasiemski (2016), suggests considerable merit to subjective experience and its impact.

Critical knowledge is fundamentally objective and specific. This kind of knowledge appears to be valued more highly than subjective knowledge, as seen by the authority provided to a HCP relaying information about MS versus an individual explaining their experiences. This suggests that societal thinking is framed in a Positivist Realist epistemology. De Long (2000) also consider that culture shapes how knowledge is prioritised, legitimised, and distributed.

Critical knowledge providers can provide insight of specific fields, for example, employment law. The combined and potential resources that can be gained from a network of social relationships is called social capital. While variability of knowledge can act as a barrier to knowledge integration in a social group, frequency can facilitate the socialisation of knowledge (A. H. Gold, Malhotra, & Segars, 2015). Increasing opportunity for critical knowledge and knowledge integration could be useful to reduce stigmatisation or false assumptions of MS. Despite this, the substantial importance of subjective experiences is evident in a study by Clayton, Rogers, and Stuifbergen (1999), which reviewed unsolicited qualitative data provided by PwMS to a quantitative survey. Participants provided additional qualitative information, even with clear writing difficulties, in order to ‘complete the context’.

It was noted by all participants the link between awareness and understanding. Some participants cited particular cultural events such as the Paralympics, which were hosted in the UK in 2012, as positive impact factors to increasing public awareness of disability and MS. Athletes such as Kadeena Cox have raised the profile of MS. Recently, a high-profile actress, Selma Blair revealed her diagnosis of MS (British Broadcasting Company (BBC), 2018). It can be argued that stigma occurs when something is not the "norm"; thus, to normalise MS via public awareness reduces the chance of stigma.

Increasing visibility also promotes cultural and societal changes. "*When we give visibility for our true self to come out, it takes [that] shame away. It allows the world to see, "You're not so scary, you're actually really fabulous…"* – Van Ness (2019)

The *route to knowledge* could be influential in how it is perceived. *Internal knowledge*, which is acquired through lived experience, may form strong, subjective belief systems which are difficult to shake. On the other hand, intentional learning may be more objective and be perceived with more validity.

Gold et al. (2015) propose that knowledge is created through two key processes: combination and exchange. How knowledge is integrated (i.e., learned) is dependent upon technical, structural, and cultural infrastructures. While Gold et al. (2015) discuss this in the context of enhancing knowledge management in organisational practices, these theories can be translated to wider society, and are seen here in terms of MS knowledge. For example, Gold et al. (2015) discuss the positive impact of technical infrastructures, such as information technologies for knowledge sharing. Participants in this study discuss the impact of the internet in sharing and increasing knowledge of MS. A study by Hall and Widén-Wulff (2008) found that knowledge exchange is mediated by social exchange relationships. As such, where social capital is high and social exchange relationships are positive, knowledge is exchanged more readily and at lower cost.

These interviews highlight the importance of lived experience to how humans learn, form beliefs, and perceive the world. The rise of behaviourism at the turn of the 20th century saw the link between direct experience and expectancy (i.e., conditioning). Later on, social learning theory explained how individuals can learn through watching others (Bandura, 1977; Berger, 1980, p. 49). Patterson (1979) stressed the role of the surrounding social network to elicit changes to individual behaviour. As such, it is relevant here that the behaviour and attitudes of UK society, or at least an organisational society, needs to promote change in order to directly affect the experiences and behaviours of its workers.

Further, Piaget's (1972a, 1972b) theories on cognitive development account for how lived experience might form false assumptions. Operational thinking contributes to how we perceive and make sense of our experiences. As humans evolve from concrete to formal operational thought, we are able to adapt our beliefs and understandings. However, this may be more difficult for some ideas than others and is particularly challenging if we are not met with poignant enough experiences to adjust our beliefs, or if these new experiences do not provide sufficient argument to re-balance our perceptions.

Many professionals discussed how their direct experiences with PwMS had equipped them to respond better to the challenges PwMS might be facing. Although participants in this group did not have a lack of direct experience with MS, a number of professionals rationalised that false assumptions and stigmatisation of MS were likely due to a lack of personal experience. Addressing issues of limited knowledge through effective sources of information should be considered as a means to reduce stigmatisation of MS.

Professionals in this study often noted signposting when discussing successful strategies to support PwMS in paid work. Signposting is a skill that allows collective knowledge to be utilized efficiently. The concept of this is supported by social capital theory, by which value can be elicited from interpersonal relationships and their capacity for achieving desired outcomes (Seibert, Kraimer, & Liden, 2001). Social capital results from a collective knowledge. Knowledge sharing within communities *"…reduces the cost of information, both in searching and verification and raises the levels of reliability."* (Schuller & Theisens, 2010, para.3). Thus, signposting is a useful tool in accessing knowledge to greatest efficiency. Professional participants noted that knowledge sharing was independent of social hierarchical structures. Further research would be useful to elicit if social assumptions of hierarchy impact perceptions of knowledge quality. De Long (2000) suggests that culture influences knowledge sharing interactions and argues that varying cultures may promote different activities of knowledge acquisition. Interestingly, HCPs appear to promote knowledge sharing bi-directionally across social categories, for example patient to HCP.

In fact, De Long and Fahey (2000) suggest that cultures where participation in knowledge gathering and sharing is essential are more likely to be effective at creating and integrating new knowledge. In the context of HCPs, where collaboration is valued, it stands to reason that knowledge sharing through signposting and intentional learning are key tools. While the healthcare profession supports knowledge integration in this way, other employment contexts may have a culture focused more on individual attainment and competitive resources.

Several professionals noted knowledge seeking in the context of information via online resources. Intentional learning requires deciphering which information and knowledge is valuable or useful, which is a key skill when navigating online resources. Mollman and Candela (2018) define intentional learning as "*a process used by learners to gain the abilities to self-direct, self-regulate, and actively engage in learning, which enables them to master their goals*." (p108). Mollman and Candela argue that such skills go beyond memorisation of information, and access higher order thinking processes. Thus, such skills are transferable to successful knowledge creation and management. In an era of high technical infrastructure (i.e., online sharing), intentional learning skills are vital to managing good quality knowledge. While A. H. Gold et al. (2015) purport to knowledge management in the context of organisational structures, their principles may apply to a wider society regarding knowledge of MS.

Further education systems in the UK often encourage intentional learning skills. Mollman and Candela (2018) discuss the benefits of these skills in nursing; healthcare professions have a culture of encouraging this kind of learning in order to provide services to patients. While some employment fields may have a culture of supporting knowledge creation, this is not true for all and could be a hindrance in terms of understanding the complex nuances of MS. Perhaps early years education systems that encourage intentional learning skills may be beneficial to reducing barriers to such knowledge integration.

Elliot (1997) explores the changing paradigms of the education system in the UK. The 60s saw a drive away from teachers as authority figures of knowledge dissemination, and a shift toward a collaborative approach to knowledge creation and what is now known as action research. Educators became facilitators of a process in which the curriculum was evaluated and debated, to provide a relevant learning experience for academics. However, Elliot further discusses how this shift saw a halt moving into the 70s and 80s, with external sources of financing to schools gaining increased control over the curriculum development and implementation. It would be interesting to further research the impact of mandatory education in the UK on intentional learning skills, and attitude to change. There may be some basis for how this contributes to future organisational cultures and acceptance of biodiversity. While Elliot remained hopeful in the late 90s that the tide was beginning once again to shift toward a pedagogically driven approach to the UK curriculum, Young (2011) proposes that modern government are driving a *curriculum of compliance* in the UK, by which memorisation of a pre-structured body of knowledge is the standard. However, Young also rejects the other extreme by which knowledge is seen as a social construct, defined by historical power relations. Thus, Young proposes that a curriculum be based initially in objective stability, facilitated by a pedagogical approach. In this way, intentional learning can take shape as a priority to academics and it may be useful to future social processes.

Sum and Jessop (2013) describe how the economisation of knowledge is impacting higher education systems. Education and knowledge are moving to the forefront of industry and global competition. While this may provide momentum to knowledge innovation, Sum and Jessop also highlight the impact of this on the labour market, shifting responsibility onto individuals to become employable through distinctive skills and adaptabilities. It is worth noting here that this thesis is not exhaustive of the vast and complex literature on education, knowledge management and the political and social structures that impact these.

We have seen that PwMS may or may not associate with the label of ‘disabled’. One healthcare professional in this data set also alluded to the complex systems of self-identity, changing identity, and identifying as disabled or not. However, several participants used the terms “MS” and “disabled” interchangeably when discussing situations relevant to PwMS. This is not to say that this professional group is making grand assumptions about an individual’s abilities, but rather that it is a socialised norm to categorise PwMS under the umbrella of “disability”. This can be a means for professionals to determine rights and responsibilities for the purposes of legislation.

The activities of labelling, categorising, and creating a narrative of disability is a means of asserting “bio-power” according to Foucauldian theory (Tremain, 2006); the categorisation of ‘disabled’ creates a fundamental norm of what the human body is/does, and therefore asserts itself above other functions of being. Organisation of charities and medical research, creating a demand for these defined categories, works as a tool to subjugate those that fit the disability criteria. However, more recent shifts have also seen disabled groups assert power on their society; expectation of equality in law is evidence of this. Thus, power does not necessarily mean oppression; power is simply the requirement of action. This can serve to benefit the subject in certain cases. Power processes are a key principle of Emerson’s (1976) social exchange theory; where two parties hold interdependency for resources, exchange relations and power dynamics are balanced. However, power inequality may occur where the exchange relationship becomes imbalanced.

Labels, according to Link and Phelan (2001), are a means of selecting factors that are socially significant. Some human differences are prioritised whereas others are overlooked, and this is dependent largely on social processes and cultural developments. A popular example of this in action is Jane Elliot’s eye colour experiments in a school classroom, for which she divided classmates by the colour of their eyes; blue-eyed and brown-eyed (Bloom, 2005; Peters, 1985). Initially, she told the blue-eyed students that they were smarter and superior while the brown-eyed students were berated. On the next day, she reversed this. Despite previously being a cooperative and high-achieving class, Elliot saw that the students took on the roles as given, with the “inferior” group performing worse on tests and behaving as “inferior”. In contrast, the “superior” students became discriminatory in their interactions with the other group. This shows, in action, the process of discrimination and stigmatisation as outlined by Link and Phelan (2001). First, human differences are defined and labelled. Dominant cultural beliefs parallel particular labels to undesirable characteristics and so those that are assigned such labels are categorised (e.g., disabled). People who are assigned these labels are then stigmatised and discriminated against. This may or may not be a conscious process and is more likely a by-product of social norms and assumptions.

Particularly relevant to MS is the dualistic understanding of hidden disability. Those who *"trespass the borderlands of identity categories*" (Valeras, 2010, para. 15) face on-going negotiations between 'normal' or 'other' labels, e.g., disabled, or able-bodied. The assumptions of polarity in these terms simply do not fit to the experiences of people with invisible conditions.

The category of disability itself remains to be agreed upon. There have been various models of disability proposed in an attempt to define this term; from the medical model which lay focus to a perception of fault in the individual's abilities to function, to the social model, which views disability as a cultural phenomenon (Edmonds, 2005). Despite its influence on breaking down social and political barriers for people with the label of disabled, Shakespeare (2006) reflects that this social model simply shifts blame onto society as the oppressor and does little to address the everyday limitations people with disabilities are presented. More recently, Swain and French (2000) propose an Affirmation model, which they argue attempts to remove the narrative of personal tragedy associated with disability. While not all PwMS identify as disabled, in terms of policy application, this is the category under which most PwMS will find themselves under. Perhaps most relevant to the employment setting is the rights-based model, which has been central to development of equality policy globally (Degener, 2016). This model focuses on the concept that all humans, regardless of impairment or functioning, have fundamental rights and deserve dignity.

Knowledge of what MS means and how it impacts an individual is important in employment matters. A manager with a limited or false understanding of MS may make misguided adjustments or inappropriately revoke responsibilities of the employee with MS. As stated by Foster (2007), "*Disability is commonly negatively equated with inability…*" (p.80). Her research highlights the importance of providing education that aims to counteract misconceptions related to people with disabilities in the workplace.

Stafford and Scott (1986) describe norms as *"depictions of 'ideal' persons, shared beliefs as to what individuals ought to be (behaviourally and otherwise).*" (p. 81). For PwMS the negative impact of social norms is two-fold. Firstly, MS manifestation is often not congruent to a typical illness trajectory. This can place PwMS in a battle against legitimisation of their condition and thus their needs. Second, workplace norms in the UK do not offer the flexibility that may be more beneficial to an uncertain condition like MS. These workplace norms are explored in Chapter 4 under the theme of the *'Ideal' worker* and again, in the discussion chapter (Chapter 7) of this thesis.

Uncertainty of MS is a common concept, and is well discussed in current literature (e.g. Bogenschutz, Rumrill Jr, Seward, Inge, & Hinterlong, 2016; Dennison, Moss-Morris, & Chalder, 2009). A significant difficulty that healthcare professionals and employers face with implementing actionable support is this uncertainty of MS. HCPs in this data set discussed the incongruence between information requests and the type of information they could provide. While an employer or organisation with limited knowledge of MS may seek quantifiable information, this is tricky with MS and healthcare providers must balance this without discrediting the true impact of MS on the individual.

Fatigue is a well-documented symptom for PwMS (e.g. Brown et al., 2009; Hildebrandt & Eling, 2014; Lobentanz et al., 2004) and its impact on work is demonstrable (Flensner, Landtblom, Söderhamn, & Ek, 2013; Glanz et al., 2012). However, non-MSers, including employers and colleagues can often conflate fatigue with tiredness. The Neurological Fatigue Index (Mills, Young, Pallant, & Tennant, 2010) is a validated scale for measuring fatigue and provides clear parameters to defining fatigue in MS. While this is useful in helping health professionals to determine symptom impact from fatigue, it does not address the incongruence in understanding of the term by regular associates for PwMS. Getting across the differences between ordinary tiredness and fatigue could be useful in providing a source of understanding that enables employers to support appropriate workplace adjustments.

Theme 2: Structures of Support

All participants were at least in some part aware of legislation relevant to PwMS in the workplace, most notably disability discrimination laws. The benefits of these laws to support and protect PwMS from unjust barriers to work were noted, although the difficulties of implementing such equality measures appeared more complex in practice. Interpretation and enforcement of such laws may lack consistency. Bell and Heitmueller (2009) argue that such legislation has simply shifted the burden of adjustment costs from the individual to the employer, thus willingness to support employment of people with disabilities may indeed have decreased. Further, the authors suggest that due to the onus of discrimination evidence falling to the plaintiff, uptake and enforcement of anti-discrimination laws may be relatively low.

Despite legislative protections to people with disabilities, a Swedish study found that those with invisible illnesses were less confident to disclose to potential future employers, for fear of it costing them a job offer (Norstedt, 2019). Employers in the same study appeared to view disclosure as an opportunity to assess applicants ‘fit’ to the job based on whether adjustments were reasonable. HCPs in this study suggested strategic disclosure as a useful device to avoid these risks whilst accessing legislative protections. However, the guaranteed interview scheme, which one employer alluded to, would require potential post-holders to disclose on application.

HCPs in this study appear to see themselves as advocates for PwMS in terms of their workplace rights, and strategies to ensure employers met their obligations were discussed. This included strategic disclosure, such as speaking first with the occupational health department. According to HCPs, willingness of employers to meet their obligations seemed more aligned to their personal attitudes and the quality of interpersonal relationships, rather than a sense of legislative obligation. Employers from this group however focused more heavily on the obligation side. This study does likely fall victim to bias in that the employers willing to speak to the researcher about their experiences were more than likely those who had had positive experiences and met their legal obligations successfully. Despite efforts to include employers with a range of experiences, employers with less positive experiences or non-complaint employers are unlikely to want to lay themselves vulnerable to public speculation. This is unfortunate as this research seeks to understand all experiences in order to learn how to reduce negative impact, rather than forming any moral inferences from previous events.

As pertained to in the introduction, legislation related to discriminatory actions or behaviours, as well as worker's protections are in place in the UK, and can show disparities with other Anglophone countries. As this study is specifically focussed on experiences in the context of the UK, and indeed interviews have been limited to residents of England, it is UK legislations only that are relevant to these findings. Legislative protections include the Equality Act 2010 (preceded by the Disabilities Discrimination Act 1995, which may still be referred to). Legislative text related to employees with disabilities is notably open to subjective interpretation, such as what is considered 'reasonable' in making workplace adjustments. However, despite the rise of Oliver's (1983, 2013) social model of disability, the DDA that was introduced in 1995 was framed around the discredited medical model of disability, as described above (Foster & Fosh, 2009). The Equality Act 2010 has failed to update this, continuing to frame disability as an individual problem.

The success of managing employment barriers for PwMS may be influenced by the quality and level of relevant services accessible. Employers and healthcare professionals commented on the different services they were able to utilize to support PwMS in work. Some noted a perceived disparity in the services available. This perception is supported by a scoping review (Roddam et al., 2019), which highlighted potential barriers to specialist services for PwMS, including lower socio-economic status, mental health conditions and African-American ethnicity. The authors also noted locational factors, such as regional differences in available services as well as an increase in barriers to those living in rural locations. This conclusion is reflected in the present study by participants, who note that services available can vary by UK region. A Green Paper confirmed that services can vary across the UK for both mental health support and musculoskeletal conditions (Department for Work and Pensions & Department of Health, 2016). Further, official statistics published by the UK government found that only 51% of employees reported having access to occupational health services at work (Department of Health and Social Care & Department of Work and Pensions, 2019)

As well as accessibility disparities, there is evidence in the literature of inconsistencies in how these services are received. Ceolta-Smith, Salway, and Tod (2018) found that frontline staff responsible for facilitating and managing the Department for Work and Pensions (DWP) employment support programmes showed a lack of consistency in their approach as well as training provided to staff. The role can manifest in different forms, including either health promoter or health monitor. These two approaches could be fundamental to how a person with MS experiences trying to access financial and employment support.

Services available to support PwMS in the workplace may also be beneficial to supporting the employer. Employers that offer a specialised staff body dedicated to human resources management reduce cognitive burden to managers in negotiating appropriate adjustments; future research may be useful in determining the impact of employment support teams to manager capabilities and experiences, and the subsequent effect to employees.

Although participants did briefly discuss the potential benefits of financial support to employers for providing adaptations, the sub-theme of *Finances* is primarily related to the anxiety individuals with MS experience toward their financial security. A key contributor to this anxiety seems to be the welfare state in the UK. In particular, the DWP have overseen some major shifts in the processes involved in applying for and receiving welfare support. This is indicative of the current political climate.

The MS Society (2019) reported on the detrimental impact of new welfare reforms to Personal Independence Payment (PIP) in the UK. PIP was implemented to provide financial support to people with disabilities in activities of daily living and is assessed independent of employment status. Welfare support is also available in the UK for people not in paid work or on low income. The MS Society argue that loss of PIP by PwMS as a result of the reforms will contribute to a rise in employment support welfare claims, as this loss of PIP will make many unable to continue work. Their report also highlights that loss of PIP support has resulted in higher costs to NHS services, due to increased demand. Recent changes to PIP assessment have placed additional strain on PwMS in managing the challenges associated with continuing work, including psychological burden of financial hardship.

Notwithstanding financial needs, it appears that the stress related to a lack of financial security contributes heavily to the work experiences of PwMS. This stress can contribute to exacerbation of MS symptoms and even accelerate progression (S. M. Gold et al., 2005), ultimately increasing the likeliness of needing to withdraw from paid work. Financial security is important because the UK functions under a capitalist economy. While there are numerous capitalist varieties, the basic characteristics of capitalism are private ownership, wage labour, accumulation, profit, and competition of capital. The UK business model is distinct from other European models, and the recent withdrawal from the European Union is set to create additional challenges to this model at the detriment to the UK labour market (Lavery, Quaglia, & Dannreuther, 2018).

It is important to consider the economic climate of the UK in recent years when exploring the context of paid employment. The UK experienced financial crisis in 2008, which the Conservative-Liberal Democrat coalition, and later Conservative led government, was able to utilize for their own political agenda (Lavery, 2017). The Conservative ‘two-nation’ strategy created moralised antagonisms, by which a narrative of distinct social groups was constructed to legitimise political moves. These included in-work groups versus welfare claimants as well as public versus private sector workers. Lavery (2017) provides an in-depth analysis of the Conservative government’s strategies to gain support for and implement interventions to disproportionately affect low-income households, those reliant on welfare support and the public sector. These political manoeuvres have led to societal constructs of ‘undeserving’ welfare claimants, stigmatising the use of welfare support and increasing psychological impact to those undergoing financial hardship. In contrast to this, Morgan (2013) argues that there has been a positive shift of the welfare state in terms of family-work policies. Specifically, parental leave and childcare costs have seen changes that allow families to improve their work-life balance. This interestingly continues to fall into the narrative of the moral ‘in-work’ group being rewarded for their societal contributions and social value.

Theme 3: Capacity for Support

The capacity of an organisation to support an individual in the workplace appears to centre around two sub-themes: *Organisational culture* and *Organisational practicalities*. Although separate themes, the two are intertwined, with culture crucially providing a backdrop for what might be considered ‘practical’ or achievable. *Organisational culture* plays an important role in how barriers and facilitators are managed at work for employees seeking reasonable adjustments. An Australian study found that greater empathy, perceived legitimacy of the condition, necessity for productivity and lower perceived cost were all linked to likelihood of accommodations made. Although Telwatte, Anglim, Wynton, and Moulding (2017) concluded that employers were generally receptive to making reasonable accommodations and tended toward a culture of support, those requiring accommodations for psychological disabilities were less likely to see these granted due to a perception that these are less reasonable and less necessary for productivity. The prevalence of psychiatric comorbidity in MS such as anxiety or depression is high and so this presents an additional potential barrier to acquiring the right support in the workplace (Marrie, Cohen, et al., 2015; Marrie, Reingold, et al., 2015).

De Long and Fahey (2000) said “*At the deepest level, culture consists of values, which are embedded, tacit preferences about what the organisation should strive to attain and how it should do so.*” (p. 115). They pose that organisational culture directly influences behaviour, which subsequently informs how knowledge is prioritised. They argue that knowledge shapes decision making, and thus organisational culture may be key to negotiations regarding workplace adjustments.

A. H. Gold et al. (2015) also discuss organisational culture in the context of knowledge management. They argue that organisational culture is central to innovation and allowing individual knowledge to be integrated at an organisational level, particularly tacit knowledge. Innovative and flexible approaches to work can help employees with MS make the best use of their abilities, thus benefitting the wider organisational community. Participants in this study noted that organisational cultures in the UK do not often appear conducive to knowledge management in this way. Instead, organisational cultures were perceived to be limited by social norms of work, in line with Williams' (1999) portrayal of the ideal worker.

Included in such organisational culture, Professionals note a reluctance to take sick leave and the detrimental impact of this for PwMS. A culture of health within organisations is beneficial both to the employee and employer. For example, Fabius, Frazee, Thayer, Kirshenbaum, and Reynolds (2018) demonstrate that such an organisational culture leads to reduced health care costs; with health and wellbeing programmes leading to increased productivity in the workplace, lower absenteeism, and reduced disability, both work and non-work related. Organisational cultures geared toward employee wellbeing may result in positive outcomes for both parties; employees feel more valued as workers and are therefore more committed and productive within the workplace (Renee Baptiste, 2008).

Factors such as sector type and organisational size may play a role in how likely an employee with MS is to be supported. Hoque and Noon (2004) found that public sector and larger employers were more likely to comply with disability employment legislation or have relevant policies in place. This conclusion was reflected in the current study, as participants tended to suggest that public sector employers were more likely to be flexible and have good policies to support PwMS to continue working. However, participants' views on larger versus smaller sized organisations varied, in terms of how supportive an employer was able to be.

Public sector employers were perceived to be more amenable to adjustments, which some participants noted could be a result of workplace cultures. The Department of Health and Social Care and Department of Work and Pensions (2019) report that the public sector saw higher retention rates of employees. The same report found that employees in the private sector were less likely to take a period of long-term sick leave, although this may be indicative of cultural demands rather than health and wellbeing.

Shifting down from organisational-level factors such as sector type and size, a key aspect of employment experiences may be the micro-cultures or interpersonal relations in the workplace. HCPs and Employers in this study note that successful work outcomes are more likely linked to good interpersonal relationships in the workplace, rather than policies. Zaheer, McEvily, and Perrone (1998) define trust as "*the expectation that an actor (1) can be relied on to fulfil obligations, (2) will* *behave in a predictable manner and (3) will act and negotiate fairly when the possibility for opportunism is present.*" (p. 143). Specifically, work relationships deal with relational trust as opposed to dispositional trust. That is, trust that is specific to the counterpart of a relationship rather than a general belief or expectancy of others. Relational trust is fundamental to these interpersonal relationships and can contribute positively to the work experiences of both employees with MS and their employers. Munir, Randall, Yarker, and Nielsen (2009) found that self-management behaviours of employees with chronic illness were primarily influenced by line managers rather than occupational health departments, further suggesting that this interpersonal relationship is significant.

Interpersonal relationships in the workplace are also significant to social resources (Seibert et al., 2001). As such, individuals with weaker social ties in their work environment may be less likely to access information, promotion opportunities or support. Scott, Colquitt, Paddock, and Judge (2010) found that employees whose managers showed higher levels of empathy had better work productivity and less somatic complaints than those whose managers were less empathetic. Employees with MS whose managers display higher empathy may be more successful in continuing work.

When investigating the capacity of employers to support employees with developmental disabilities, Rashid, Hodgetts, and Nicholas (2017) highlighted the key role of employment support staff to facilitate successful employment outcomes. In that study, participants also noted the disparity between visible and invisible conditions in receiving support. Interestingly, some participants noted that there is often more variability *within* than *between* people with disabilities, and thus to treat disability as a "one size fits all" group when implementing diversity strategies seems inappropriate. Foster (2007) supports this sentiment, arguing that impairments can impact people differently based on individual differences, job type or even daily fluctuations. Similarly, professionals in this study reflected on the broad range of characteristics that MS can include. Thus, any disability employment policies formed from generalisations may not be fit for purpose.

Organisational size features in much of the discussions around practicalities of employer support, with professionals citing smaller organisations as less able to provide necessary adaptations. Recent statistics by the Department for Work and Pensions (DWP) suggest that employees working for small organisations are less likely to have access to occupational health services and employees with disabilities are more likely to leave work compared with large employers (Department of Health and Social Care & Department of Work and Pensions, 2019). The report did not find any significant difference in proportion of employees returning to work following adjustments. However, smaller employers did see a greater discrepancy in retention rates between disabled and non-disabled employees. This suggests that larger employers may be more successful in implementing adjustments to retain employees with disabilities, including those with MS.

Finally, the specific type of work can be influential in how an individual with MS experiences continuing work. Jakobsen (2009) identified two types of work in terms of flexibility: active jobs and high strain jobs. High strain jobs require the worker to adapt around the needs of the job, whereas active jobs can be adapted around the needs of the individual. Active jobs are likely to provide much better outcomes for individuals with MS, who may require flexible working styles or adaptations to continue in their role.

Theme 4: (Three-legged) Responsibility Stool

As MS can present as an invisible condition, individuals with MS may be faced with making a disclosure decision at work. Professionals in this group generally agreed that while disclosure is a personal choice, disclosing is overall beneficial to staying in work. This sentiment is reflected in the literature (Kirk-Brown & Van Dijk, 2014; Kirk-Brown, Van Dijk, Simmons, Bourne, & Cooper, 2014). Despite the benefits of disclosing, participants noted that risks are usually linked to social factors, such as stigmatisation. An organisational culture that promotes diversity and acceptance would likely reduce non-disclosure and increase the ability to access appropriate support. Due to its variable pathogenesis, individuals with MS are in a position that they may need to outline how the disease is specifically impacting them in order to negotiate appropriate adjustments.

In addition to legislative responsibilities, which Professionals seemed duly aware of, the responsibility of the employer primarily seemed to be perceived in a morality context. That is, it was considered morally commendable to support employees with identifiable needs for adjustment.

Foster and Fosh (2009) pose that the use of the medical model to shape disability related legislation in the UK (i.e., DDA 1995, Equality Act 2010) conceptualises individual employees and their impairments as the problem, rather than organisational structures. Thus, although the employer may be proficient in their legal obligations, considered in context, this does not hold them particularly accountable for addressing employment barriers that disabled people, including PwMS, may face.

That morality is prioritised before legal obligations then is perhaps a useful approach, although difficult to implement in wider society.

Contrary to this study, Foster and Fosh (2009) found that often employers lacked proficient comprehension of their legal obligations. A lack of organisational procedures created various barriers for employees requesting workplace adjustments. However, this study is limited to only the experiences of employers in the public sector. Public sector employers see higher job retention rates and better access to occupational health services compared with the private sector (Department of Health and Social Care & Department of Work and Pensions, 2019).

Participants in this study appeared to consider the responsibility of managing MS at work a collaborative one which included the healthcare professional. While the onus on the individual with MS was primarily focussed on a responsibility to communicate their personal experiences with MS, the HCP was deemed to be responsible for providing education to others from a critical objective standpoint. Interestingly, this shows a possible shift in the power dynamic between patient and health professional, as well as a change in how subjective and objective knowledge types are valued. Raphael, Hawkes, and Bernat (2013) explore how a previous physician-centred approach saw HCPs withhold key information, such as diagnoses, from a patient in order to preserve the patient’s ‘best interest’. This has now shifted to a shared decision process, focussed on patients’ rights to know so they can participate in decisions about their treatment. HCPs have a responsibility to disclose medical information about the patient to them so that they can be a part of this decision process. This study implies HCP responsibilities are now moving beyond this, in that the HCP is now seen to have a duty to educate and share their knowledge in order that patients and those they interact with can make more informed decisions.

Brennan (2002) advises that healthcare professionals’ primary responsibilities lie in promoting quality of care. This can be realised through individual patient care, quality of care to the patient community, as well as ensuring education and continuing professionalism of high-quality healthcare. Brennan notes, however, that with the increased responsibility of healthcare professionals, there is an element of control or power. He argues that, by definition, professionals are those controlling a certain knowledge and that this can raise questions as to their use of this power as an occupational group. Despite this, he also argues that healthcare professionals can embrace civic professionalism, as a social reform, to re-address the principles of altruism that this occupation embodies. While this growing distrust may be relevant in the US, where healthcare is more financially incentivised, public perception in the UK may differ.

Recently, there has been a push toward the concept of work as a health outcome. Black (2008) reviews the ways in which work and health are interrelated as well as the ways in which health professionals can facilitate good work for better health. In response to this movement, the 2019 Healthcare Professionals’ Consensus Statement on Health and Work outlines a commitment from the healthcare professional community to incorporate relevant discussions about work into their patient care, with an aim to reduce avoidable health related worklessness (Academy of Medical Royal Colleges, Royal College of Nursing, & Allied Health Professionals Federation, 2019). Worklessness here refers to both long-term unemployment or job loss.

Theme 5: Life Journey

Diagnosis of MS is a significant life-altering event. Continuing to engage successfully in meaningful activities, such as employment, relies initially on adjustment. One HCP considered the adjustment journey following MS diagnosis alongside the Y-shaped model (Gracey, Evans, & Malley, 2009). Although originally developed in response to rehabilitation for acquired brain injury (ABI) patients, the concepts of this model are applicable to any individual who has experienced a traumatic or significantly life-altering event. The process of adjustment involves exploration of the current self in context as well as the ‘aspired-to’ self that existed before a life-altering event; in resolving various discrepancies and addressing threat-responses related to self-regulation, the individual can build an updated, realistic sense of self.

While the in-work participants with MS for this study discussed MS as a spectrum that is different for each person, professionals pertained also to the different stages of MS an individual can be dealing with. An individual in the first stages of diagnosis will likely have very different experiences and needs to someone at a later stage of MS. These different stages of MS may be consonant to the *adjustment process* in the 1a model. Physical impact of MS increases with age and disease duration (Jones et al., 2013). That said, more subjective measures, such as personal factors and belief systems may be more likely to impact MS management than objective measures such as disease duration and age (Wilski & Tasiemski, 2016). Further, Green, Cutter, Friendly, and Kister (2017) found that invisible symptoms such as fatigue are more influential to self-reported health perceptions of PwMS than physical impact. Wassem and Dudley (2003) concluded that an intervention focused on adjustment saw improvements in symptom management for PwMS, suggesting that adjustment plays a key role in its impact.

Depressive symptoms and anxiety are related to self-efficacy and coping strategies in those newly diagnosed with MS, with anxiety also correlating to employment status (Tan-Kristanto & Kiropoulos, 2015). Self-efficacy also appears to predict work instability over time (Ford, Wicks, Stroud, & Tennant, 2019) suggesting that psychological factors are important in ongoing employment retention.

One participant made reference to Maslow’s (1943) theory of human motivation (commonly referred to as Maslow’s hierarchy of needs) in reference to meaningful employment. Maslow recognised that motivation is culturally mediated; in the UK work culture may determine motivation to maintain paid employment. Paid employment provides safety; although Maslow described that these might only come in to focus once basic physiological needs are met, in modern society, it is the security of employment that in fact allows these basic needs to be met. Basic physiological needs are capital in UK society; shelter, food, warmth and even water are financialised resources. Paid employment provides financial resource which can be exchanged for these. Privatisation, as a backdrop to capitalist economy, enforces these exchanges.

While competition for resources existed long before capitalisation as per evolutionary theories, concepts such as inclusive fitness are evidence of the complexities of human motivation. Inclusive fitness looks beyond individual survival, gauging evolutionary success in terms of survival of kin (Hamilton, 1964). Bernard, Mills, Swenson, and Walsh (2005) developed a modernized model of human motivation which accounted for motivations not just related to individual self-protection and protection of kin, but also the larger, non-kin system and a symbolic, cultural system (i.e., legacy). Most importantly, their work recognises the importance of cultural factors and unifies behavioural, cognitive, and neuropsychological approaches. Bernard et al. (2005) pose that "*Culture, by providing an environment of shared expectations and values, imposes a certain consistency on social reinforcement and the development of cognition*." (p.133). This concept of culture as a mutually beneficial system of shared expectations is in line with the reciprocity principle of social exchange theory (Trivers, 1971). Indeed, Molm, Collet and Schaefer (2007) distinguish between direct exchange (between two parties) and generalised exchange, by which reciprocal action extends beyond the confines of the dyadic interaction to a wider social environment, forming what they term "social solidarity".

A culture which reinforces the social value of work will foster motivation to stay in work to feel valued. The social value of work goes beyond rate of employment for PwMS; meaning is acquired through benefitting others, a sense of purpose and maintaining one's identity (Meade, Rumrill, Krause, Reed, & Aust, 2016). Work is important to self-esteem and identity for PwMS (K. L. Johnson et al., 2004), which is also recognised by the professionals in this study. Kielhofner's (2008) model of human occupation (MOHO) details the impact of society and personal experience on identity, including occupational identity. Maintaining occupational participation in line with one's perceived occupational identity is central to successful occupational adaptation.

Western cultures ascribe social value to occupational identity (Unruh, 2004); what we 'do' in terms of occupation is a major part of who we are, socially. This concept is affirmed by the participants in this study. However, identity is not necessarily an individual process of formation (Phelan & Kinsella, 2009). Thus, the social organisational context in which an individual is participating in can be fundamental to their experiences and outcomes.

According to Mead (1934), the concept of the self is derived from social processes. His notes on the self as an ever-developing structure and response to both "the generalized other" as well as the social interactions between the "me" and "I" can be useful in considering the experiences of PwMS either in work, at risk of leaving work or no longer in paid work. Mead's social theories consider that the "me" portion of the self is a socially conceived entity, developed as a result of internalized attitudes, meaning-making and symbolic interactions. The "I", consequently, exists as an internal dyadic response to the "me"; thus, the actions of "I" continue to develop and re-structure the "me" through both internal and external social interactions. The impact of MS on the self can be distressing; the interactions between "me" and "I" may become more difficult or feel incoherent. Identity that is developed as an interaction between the self and work, or the organisation, may gradually shift and become unrecognisable to the individual. Adjustment is a key process here to determine how the individual experiences these shifts. Jakobsen (2009) pertains to the importance of effective adaptations both at work and at home, to allow “space” for this identity reconstruction after diagnosis of a chronic illness. The reconstruction of self and identity can be particularly problematic for individuals with invisible illnesses and disabilities, as they may strive to maintain a previous social identity or have to make a conscious decision to expose themselves to a new social identity which may be less favourable (Fitzgerald & Paterson, 1995).

First and foremost, PwMS are all individuals with personal working styles, coping skills and traits. Thus, managing work outcomes for PwMS must also utilise general occupational strategies distinct and in addition to managing MS symptoms. Participants discussed individual differences that may impact whether or for how long PwMS stay in work, including coping styles. Strober et al. (2012) found a link between employment status of PwMS and persistence as a personality factor. Carver and Connor-Smith (2010) linked various personality traits with coping styles. Further Gedik, Sorias, and Idiman (2017) found that psychosocial loss, which includes loss of employment, is partially mediated by coping styles following disability in MS.

One participant highlighted the importance of not attributing all work barriers to MS. After all, PwMS are still exposed to the array of possible challenges life can bring. It is well documented that PwMS have a higher risk of clinically significant depression (Minden, Orav, & Reich, 1987; Patten, Beck, Williams, Barbui, & Metz, 2003). Despite this, Patten, Williams, Lavorato, Koch, and Metz (2013) found no direct effect of depressive symptoms on job cessation in PwMS. Although depression was not found to be a direct causal factor to job loss, it was present as a confounding indicator among other MS related factors. Thus, managing and persistently adjusting to the myriad of challenges MS creates serves only to make staying in work more difficult.

R. E. Johnson, Chang, and Yang (2010) developed a model which outlines how commitment and self-identity levels interrelate. Their model specifies and distinguishes between three commitment types: affective, normative, and continuance commitment. Normative and continuance commitment types are espoused in perceptions of obligation, and investment, respectively. Affective commitment, however, is much more self-determined, and results from internalisation and identification with group goals and values. In addition to type of commitment, Johnson et al. (2010) describe that individuals’ self-identity operates at three independent levels: collective, relational and individual. Motivations may also be promotion-focused, or prevention driven. The complex interplay between self-identity, motivation-focus and commitments could account for how PwMS experience and make decisions about their paid employment. Further, the changes an individual may experience following MS diagnosis, and throughout adjustment, could contribute to a shift in motivations and commitments.

Strengths and Limitations

This analysis benefits from a broad representation of the varied HCPs that may be involved in MS-related health management. Thus, this study may offer key insights to wider contextual and social level structures that may influence work outcomes for PwMS. By utilising observations from HCPs, who take an outsider perspective on the experience of MS, this research can scrutinise the mechanisms between subjective experience and observable constructs.

Due to the limited sample for employer representatives, the data were considered in combination with healthcare professionals. This proved a successful endeavour in that the concepts can be contextualised in terms of those responsible for PwMS from a professional standpoint. In this sense, employers and HCPs face similar challenges and may represent a shared perspective. Professionals' responsibilities are to maintain the wellbeing of the employee with MS, though they comprise an outsider perspective of MS. By combining employers and HCPs, the potential for bias from the limited employer sample may have been reduced; HCPs were able to offer insight to varied experiences of PwMS across organisational categories.

It is also important to recognise that this research is conducted from an 'outsider' perspective. This could be argued as both a strength and limitation, with benefits and risks to both 'insider' and 'outsider' research strategies. Bonner and Tolhurst (2002) as well as Bhopal and Deuchar (2015) provide useful reviews of the benefits and disadvantages of insider and outsider research strategies.

Unfortunately, this study is limited in representing employer perspectives. It is probable employers with negative experiences were reluctant to put themselves forward for interview, thus the findings presented in this research are subject to potential bias. Additionally, identifying relevant employers was a challenge. Although PwMS taking part in the study were invited to put forward their employer or previous employer if they felt comfortable to, no participant with MS decided to do so. While measures were in place to avoid discussing individual employees during interviews, it is understandable that PwMS may have felt vulnerable, particularly if they knew of no other employees with MS in the organisation.

Conclusions

This chapter explored employment and MS from the perspective of professionals whose role is in supporting PwMS, either in the workplace or as healthcare professionals. The five key themes identified, *Knowledge flow, Structures of support, Capacity for support, (Three-legged) responsibility stool* and *Life journey* incorporate contextual factors at macro- meso- and micro-levels that may be influential to the barriers and facilitators to paid work for PwMS.

Knowledge plays a pivotal role in experiences of work for PwMS as well as those supporting them. Where knowledge is not congruent between entities, barriers such as stigmatisation or lack of suitable adjustments may arise. Strategies to share and create knowledge are beneficial in reducing experiences of invalidation and improving workplace dynamics. Where HCPs may already be utilizing useful knowledge management behaviours, employers may benefit from encouraging knowledge management methods within their own organisations. On a wider scale, knowledge management strategies could be valuable to informing national policies and structures of support. As it stands, support structures, in particular legislation and services, lack consistency in their implementation, creating further potential uncertainty for PwMS. These structures of support are the vessels that feed capacity for support; organisational culture is influenced by societal-level models. While structures of support are the vessels, knowledge remains the lifeblood.

Culturally established concepts of responsibility also influence how PwMS are supported and by whom. Social exchange processes which promote cooperation have enabled a development of societal organisation that centres around generalised reciprocity, seeing cultures function under a shared set of expectations. However, this may not to be to the benefit of people with disabilities. Specifically, PwMS may be perceived to be "breaking the rules" of cultural-level illness perceptions, organisational expectations or even morality attitudes linked to receiving welfare support.

Shifts in models of disability have played a major role in how PwMS are supported. Despite not all PwMS self-identifying as disabled, these models define the healthcare and welfare systems that PwMS may be interacting with. The UK capitalist model also defines how being in or out of work is experienced; employment is intrinsically linked to motivation and social value. Work is also important to identity and self-esteem. Thus, when changes to employment are under negotiation, either as adjustments or cessation, strategies to preserve an accepted self-identity should be considered in order to make the transition successful and effective. Finally, it is important to keep in mind the physical and psychological impact of MS directly on remaining in paid work, as well as individual factors. Encouraging knowledge sharing with professionals who are in a position to support PwMS, so that they may better understand the individual impact of MS is paramount to negotiating positive employment outcomes.

Conclusions from this analysis will be considered alongside the working group and retired group analyses in the discussion chapter, in addition to wider implications of this overall study.

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Chapter 7: Discussion

Introduction

This study has included perspectives of three key stakeholders in exploring the facilitators and barriers to paid work and Multiple Sclerosis (MS); people with MS (PwMS) currently in paid work, PwMS no longer in paid work and Professionals involved in managing PwMS either in an organisational or a healthcare capacity. While the individual analyses offer key insights, it is useful to also combine and synthesise the findings to develop a broader understanding of the overall picture in regards to managing MS and paid work in the UK. To achieve this, a core model is developed, and discussed below.

Critical realist research is concerned with the ‘generative structures’ between an objective, material reality and subjective, social interpretations of events; what Bhaskar (2013) referred to as the ‘Real domain’. Further, Critical Grounded Theory (CGT) utilises a retroductive approach to understanding mechanisms involved in the social problems under exploration. Therefore, understanding what remains applicable in the metaphysical ‘spaces’ between all three models is appropriate to this method. This core model will then be reviewed in the context of the wider literature.

Core Model Overview

The core model identifies five key themes: *In/validation, Adjustment demands, Sense of control, Social relations at work,* and *Constructing social value.*

Peripheral to this model are the structures that influence these key themes. These include *Knowledge structures, Inter-organisational structures, Socio-relational structures, and Intra-organisational structures*. Inclusion of these structures to this model is informed by the professional viewpoint, i.e., professionals involved in managing PwMS either at work or in a healthcare setting.

The model incorporates a temporal dimension, in terms of the stages PwMS may find themselves at; the period around onset to diagnosis carries its own experiences that may differ in comparison to later stage MS. Likewise, PwMS in work may have experiences that differ from those considering leaving or having left work. That said, there is certainly overlap in where these themes are relevant. Alternately, key themes may encompass the experience of PwMS at multiple stages but present in different ways; for example, during work, *Health-related* and *Occupational adjustment demands* are key priorities, whereas in leaving work, *Social adjustment demands* take on a more predominant role. Likewise, *Health-related uncertainty* may be high during the diagnosis period and in early MS but may reduce over time. That said, for some PwMS, uncertainty will continue to be high during their MS trajectory and this is reflected in the model under the key theme: *Sense of* *control*. *Health-related adjustment demands* may influence levels of *Health-related uncertainty*; where adjustment demands are realized, uncertainty may be decreased. Additionally, where occupational and social demands are fulfilled, *Occupational autonomy* may be positively influenced.

Constructing social value is presented as a step process, by which individuals first begin to assess or reassess their social roles. This is not necessarily an explicit process of reflection but may present as individuals reaffirming aspects of their self-identity that are important to them, strengthening pre-existing roles or de-prioritising others, or conforming to new social roles (e.g., “disabled”). Following identity reconstruction, or identity affirmation, PwMS may then begin to adjust how they achieve social value through exchange. *Value through social exchange* is the process of finding meaning and social value through exchanges in the workplace. Meso-level structures, such as intra-organisational and socio-relational structures affect this process, for example, organisational culture as an intra-organisational structure may influence how PwMS extract social value from their occupational setting. Further, *Knowledge structures* contribute to what is considered to provide social value.

In/validation processes and *Outcomes* are greatly influenced by *Knowledge structures*; indeed, knowledge is a precursor to *In/validation*, such that false assumptions precede stigmatisation.

The process of in/validation is explored in more depth in Chapter 4 following analysis from PwMS currently in paid work, whereas *In/validation outcomes* were reflected on by PwMS no longer in paid work (Chapter 5). PwMS might find themselves caught in such processes as early as the diagnosis period, perhaps if they are requiring time off work for appointments or are struggling with symptoms at onset. This process may continue, or recur, for the duration of staying in work and even alongside the process of leaving work. However, outcomes of *in/validation* may also arise either during work or on exit from work. Outcomes might include to what extent reasonable adjustments are met or a shift in organisational knowledge schema.

Adjustment demands include *Health-related*, *Occupational* and *Social* adjustments. PwMS may have *Health-related adjustment demands* from the time of diagnosis right through to their retirement, as MS symptoms continuously present or shift. On the other hand, *Occupational adjustment demands* become prominent when individuals are faced with making adjustments related to their occupational setting, such as managing reasonable adjustments or navigating changes to employment. PwMS will generally take on the burden of managing occupational adjustments, and this can create additional pressure for individuals. Finally, *Social adjustment demands* might begin in work, with changes to self-identity or social identities. However, major social adjustments are more prominent during the transition out of work, which presents as a major social transition. For some PwMS, retirement means adjusting socially to new identities or sources of social value.

Social relations at work is a theme that, understandably, is most prominent during time in paid work. The dialogical relationship between the sub-themes *Interpersonal trust* and *Interpersonal responses* is represented by the bidirectional arrows; as such, increase in *Interpersonal trust* can have a positive impact on *Interpersonal responses*. Likewise, favourable *interpersonal responses* can increase perceived *Interpersonal trust*. These social relations may directly impact sense of *Occupational autonomy* such that increased positive social relations lead to increased *Occupational autonomy*.

Lastly, some themes within this model represent concepts specifically identified by either PwMS still in work or PwMS no longer in work. This is not to say that these concepts do not occur for the alternate group, but rather identifies them as themes that are no longer acknowledged by each group (e.g., people no longer in work may no longer engage with their perceptions of interpersonal trust but do reflect on interpersonal responses). For PwMS who have left work, reflecting on their experiences at a distance from the workplace setting allows for recognition of certain mechanisms that PwMS still in work may not be able to identify. Such themes may be useful for PwMS still in work to consider as potential indicators of work outcomes, thus offering the opportunity for some foresight.

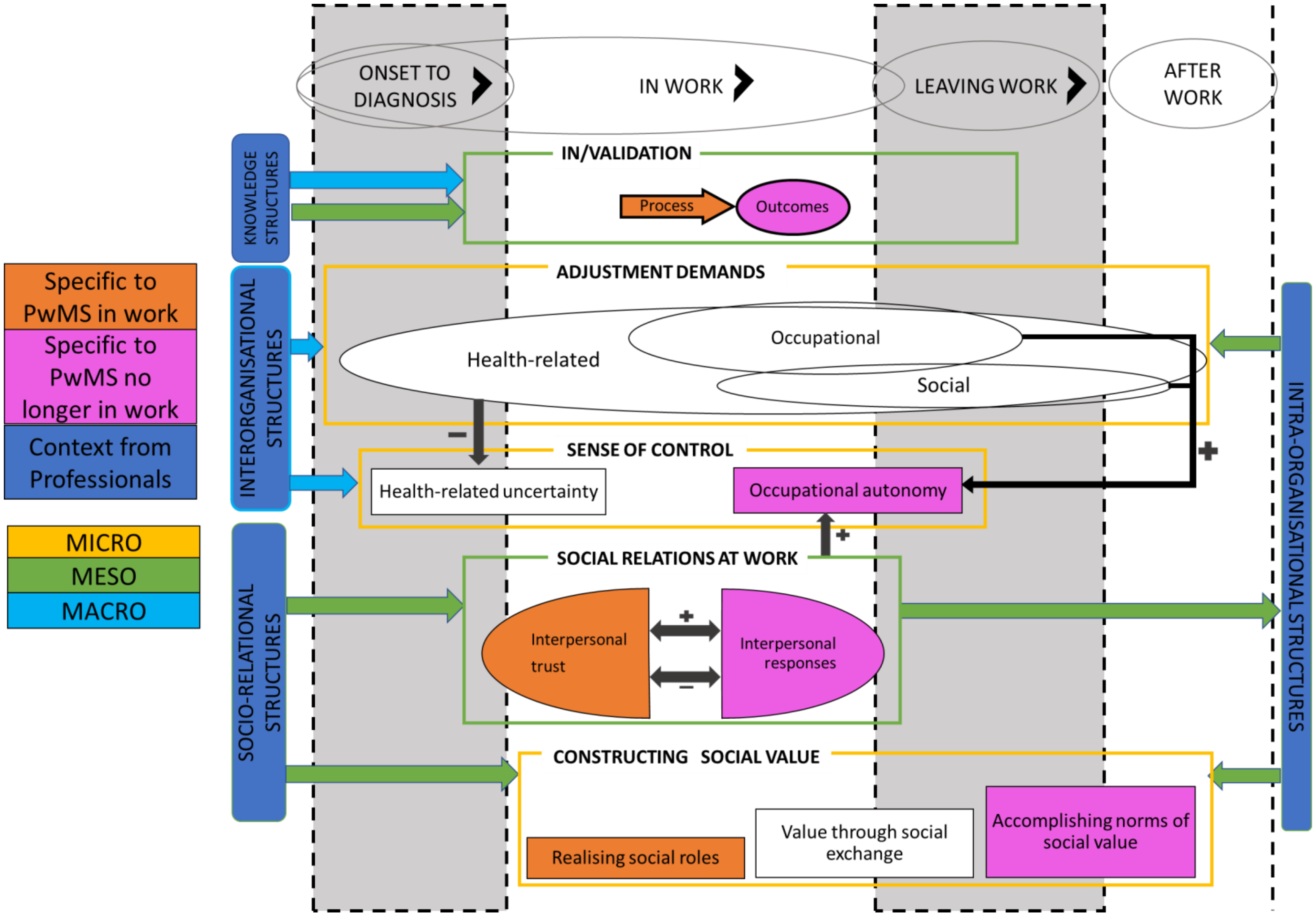

Figure 7.1 - Core model

Theme 1: In/validation (meso)

In/validation is influenced by macro- and meso-level knowledge structures. Professionals offered context that stigmatisation is a product of knowledge incongruence. Where knowledge is incongruent, misconceptions can lead to invalidation, disempowerment, and stigmatisation; challenging these false assumptions is necessary to reduce barriers to work for PwMS. How knowledge is created, shared, and managed is linked with cultural infrastructures (Gold, Malhotra, & Segars, 2015). Therefore, strategic knowledge management in the workplace and wider society may be useful in creating cultural shifts that enable empowerment of PwMS in work, reducing social barriers.

Such knowledge structures also contribute to general understanding of MS and concepts of disability (e.g., Foster, 2007). Harris (2001) asserts that disability is characterised not in relation to normal species functioning, but by strong rational preference not to be in a condition compared with possible alternatives. Harris therefore defines disabilities as differences that result in a harmed condition. Impact of MS symptoms undoubtedly presents harm to an individual in contrast to their non-MS colleagues. Harris also points out that, as per the principle of equality, societies must work to ensure that people with disabilities can access equal status, freedoms, and facilities as any other person. Thus, recognising disabilities, the harm they present and finding ways to lessen harms is important for research that seeks to improve equality outcomes. Recognising the harmed condition PwMS may find themselves in forms the basis of validation.

Theme 1: In/validation; Sub-theme 1: Process

Selby, Braithwaite, Joiner, and Fincham (2008) define emotional invalidation as "*pervasive criticizing or trivializing of the communication of internal experiences*" (p.885). This same definition can be useful in describing invalidation of MS, by which the internal experience of the condition is trivialised, brought into question, or even openly criticized.

Invisibility of MS symptoms presents PwMS with a distinct dilemma related to validation; the individual must make decisions about disclosure that may be linked with feeling invalidated (Norstedt, 2019; Valeras, 2010). However, even following disclosure, the individual with MS may find that they continually need to reaffirm their position. Where disclosure is made, PwMS may then face invalidation due to not conforming with socially constructed concepts of disability (Valeras, 2010). Areheart (2008) describes a concept of the 'goldilocks dilemma' in which individuals with invisible illnesses are rated by macro-systems as too disabled or not disabled enough; participants of this study also appeared to experience this phenomenon.

Invalidation and empowerment are distinct but highly interconnected constructs. Empowerment sees an individual gain influence, sense of control and greater participation in democratic decision-making (Christens, 2012). Validation can facilitate empowerment, although empowerment can also be a means of validation. This is because empowerment can arise as either a process or an outcome (Zimmerman, 1995). Likewise, invalidation for PwMS in the workplace occurs initially as a process, and then an outcome. The process, as described in the model in Chapter 4 identifies how PwMS may have to go through periods of validating, legitimising, and reaffirming their condition. PwMS who had left work were able to reflect on the outcome of this process, in the context of employer responses. These responses could be either validating or invalidating, and empowering or disempowering, in different points of a matrix (see Chapter 5: Theme 3: *Dis/empowerment In/validation matrix*).

Theme 1: In/validation; Sub-theme 2: Outcomes

Interventions that focus on validation as an outcome may be beneficial for PwMS. In particular, where organisations are unable or unwilling to be involved in implementing change for the employee with MS, this may be a useful intervention strategy to circumvent the negative effects of an unaccommodating organisational culture.

Blom et al. (2012) found that employees with fibromyalgia respond to invalidation at work by emphasizing their personal integrity through strengthened moral judgements; the ensuing embitterment can make managing working conditions and seeking support all the more challenging, particularly when combined with feelings of helplessness. Thus, reducing invalidation in the workplace may help to reduce additional barriers for PwMS, such as lack of support and inadequate adjustments. The use of moral emphasis as a resource strategy is interesting to consider in the relationship between trust and social exchange theory. Interpersonal trust influences exchange relationships (McAllister, 1995). Specifically, integrity-based trust has a greater impact on exchange relationships and reduction of exchange transaction costs in an organisational setting compared with competence-based trust (Connelly et al., 2015).

Kool, van Middendorp, Boeije, and Geenen (2009) found that invalidation can be quantified and structured according to two key concepts: active negative social response and lack of positive social response. Such research is useful in development quantitative instruments to measure and identify invalidation. Measurement tools can help to screen for risk and identify where intervention strategies may be necessary. In terms of intervention considerations, self-efficacy and acceptance may offer some protective factors against invalidation for people with chronic illness (Cameron, Kool, Estevez-Lopez, Lopez-Chicheri, & Geenen, 2018). Thus, interventions that focus on increasing these factors may be useful for PwMS at work.

Theme 2: Adjustment Demands (micro)

PwMS are making continuous adjustments in the workplace and when leaving work. These fall into three broad categories. Adjustments specifically related to their MS symptoms/health management, adjustments related to their occupational situation and social adjustments. Occupational adjustments include navigating reasonable adjustments at work as well as managing transitions such as changes at work or retirement. Social adjustments include factors such as self-identity and social value.

Such adjustments may also have implications for organisational or even interpersonal exchange relationships. Social exchanges carry an explicit or implicit set of negotiated expectations or ‘rules’ (Cropanzano & Mitchell, 2016). However, where PwMS disclose a diagnosis of MS, they may be faced with re-negotiating previously agreed rules of their employment. Some employers may construe this (not necessarily consciously) as ‘breaking the negotiated rules’ and respond negatively.

Adjustment demands are influenced by both inter- and intra-organisational structures. Inter-organisational structures include the UK capitalist system and culture of work. Legislation and policies contribute to how and what adjustments can be accessed, and the social norms that dictate these. Intra-organisational structures, such as organisational culture, have a similar local influence. Organisational culture may also affect level of social support, which has implications for social adjustment demands.

According to the Job-demands resources model (JD-R; Bakker & Demerouti, 2007), people are at risk of leaving work when their job demands outweigh their resources. This appears to fit to the context of PwMS, with additional consideration needed for MS-related demands, including symptom impact and socio-relational challenges. Strategies to reduce risk of early job loss should have a holistic focus on MS symptoms and job demands, while remaining open to trajectory changes. Further, reasonable adjustments can be considered a resource, alongside employer support in managing these. Figure 7.2 shows a simplified model of how the JD-R theorises work-related outcomes (represented by the y-axis arrows).

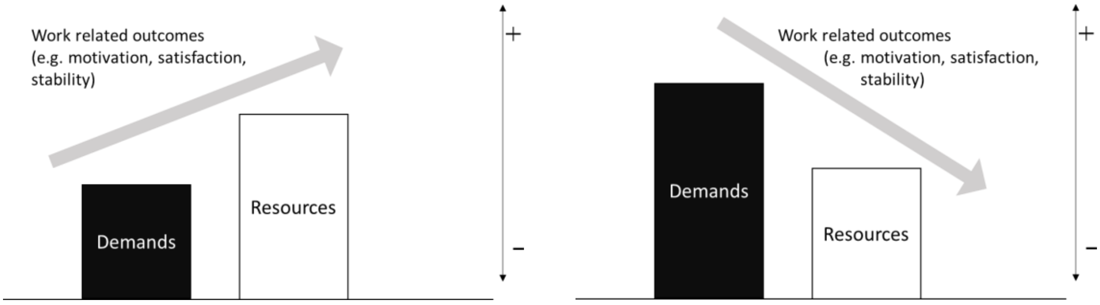

Figure 7.2 - Job-Demands-Resources Model: a simplified version

Theme 2: Adjustment Demands; Sub-theme 1: Health-related

Health-related adjustments are likely to be a demand faced by most PwMS irrespective of work status; how employers respond to these adjustment needs, and how successfully these adjustments can be implemented to contribute to reduced symptom impact however are key to successful job retention. Simply put, if an individual faces barriers to symptom management, there will be a knock-on impact on their ability to work well. The burden of symptom impact on work outcomes has been well-documented in the literature (O'Connor, Cano, Ramio i Torrenta, Thompson, & Playford, 2005; Raggi et al., 2015; Rao et al., 1991).

Although symptoms pose a challenge to managing work, rather than the symptoms themselves being a crucial barrier, it can be the barriers to developing strategies around these symptoms that lead to work cessation. PwMS who face challenges with managing symptoms at work are more likely to leave work early (Simmons, Tribe, & McDonald, 2010). Therefore, exploring strategies to reduce symptom burden early is an important first step in reducing risk of job cessation for PwMS looking to stay in work. However, due to the uncertainty characteristic of MS, it can be challenging to identify appropriate individualised strategies. Where PwMS can work collaboratively with their employer to determine suitable symptom management strategies, this will be beneficial to work outcomes and reduce the individual burden of strategizing.

Theme 2: Adjustment Demands; Sub-theme 2: Occupational

Occupational adjustment demands encompass determining, negotiating, and implementing reasonable adjustments at work as well as navigating transitions such as changes to work role or duties. Such transitions might include changes to working hours, reduced responsibilities (elected or not), reduced capacity at work, extended leave from work, or retirement. Thus, accumulative to the often-physical burden of symptoms, PwMS are faced with the psychosocial and cognitive burden of managing these operative adjustments at work. Despite analysis from the Professionals subset (Chapter 6) indicating that responsibility is perceived as a joint endeavour between PwMS, employers and healthcare professionals, interviews with PwMS (Chapters 4 and 5) indicated that a significant portion of the responsibility fell to them; particularly, the mental burden of managing change. Notably, there appears to be a lack of adequate support for PwMS during the process of retirement and after leaving paid work.

In her 2007 study, Deborah Foster found that Employer’s understanding of their legal obligations varied, with physical adaptations or equipment requests more likely to be comprehended by managers as necessary and reasonable. Even where legal obligations were met, the process of acquiring workplace adjustments was not always timely, resulting in employees experiencing substantial and unnecessary disadvantage at work. Further, this process resulted in negative effects of stress and ill-health, and in some cases, workplace bullying.

Theme 2: Adjustment Demands; Sub-theme 3: Social

Social adjustment demands present a less tangible barrier for PwMS in the workplace. Social identity shifts and self-identity reconstruction are early adjustment demands that PwMS may face, following a new diagnosis (Barker, das Nair, Lincoln, & Hunt, 2014). Further, occupation plays a significant role in identity construction ((Kielhofner, 2002; Laliberte-Rudman, 2011), and so leaving work, particularly if earlier than expected, can be distressing for PwMS. Identity also plays an important role in how PwMS experience their condition (Charmaz, 1995), and so interventions toward positive identity reconstruction may be useful in managing work and MS. PwMS are better able to develop adaptive coping styles and positive identity reconstruction where they have a secure family base in order to safely explore identity reconstruction (Barker et al., 2014).

Adjusting to potential shifts in goal attainment, such as the prospect of leaving work earlier than socially perceived norms can create additional psychological and psychosocial burden for PwMS. Goal-seeking behaviours and positive goal-adjustment may be influenced by self-efficacy levels (Bandura & Cervone, 1983). Adjusting previous held goals and beliefs through psychological intervention in order to develop coping and goal adjustment strategies may be useful in reducing the risk of leaving work early. Further, self-efficacy may positively predict physical and social functioning in MS (Schmitt, Goverover, Deluca, & Chiaravalloti, 2014).

Transitioning away from a major source of social connection can be devastating for some. Work can provide a sense of community and social support for PwMS (Burroughs & Eby, 1998). Therefore, supporting PwMS who are leaving work should include determining what social support structures may be available following retirement.

Theme 3: Sense of Control (micro)

Feeling a sense of control has a key influence on how PwMS experience their MS in work, and through leaving work. *Sense of control* can relate to either health-related factors or occupational autonomy. Interorganisational structures at the macro-level include the structures that make up employment support, financial support, healthcare systems and retirement processes. Decisions related to employment may be influenced by the support structures available. For example, if the benefits of retirement outweigh the benefits of continuing work, individuals will likely retire (Wang & Shi, 2014). However, PwMS may feel that the control over this decision is externally influenced (i.e., not within the power of their own actions). Further, availability of healthcare support may influence the impact of health-related uncertainty. Although health-related uncertainty may be increased due to the unpredictability of MS, support in managing MS through various healthcare pathways may increase the sense of control PwMS perceive related to their condition.

Theme 3: Sense of Control; Sub-theme 1: Health-related Uncertainty

Health-related uncertainty is the sense of control PwMS feel toward their health, e.g., symptom control, MS trajectory. Feeling that symptoms are well-managed is beneficial to wellbeing. Successful health-related adjustment strategies can increase this sense of control regarding health impact.

Eskyte et al. (2019) explore the 'double-uncertainty' that individuals with relapsing-remitting MS can face when making treatment decisions; the uncertainty of the MS trajectory itself alongside the uncertainty of drug efficacy or outcome. However, their analysis also highlights that treatment decisions can offer to individuals a sense of control and choice during health-related uncertainty. Tolerance to uncertainty is a helpful tool for PwMS broadly (Alschuler & Beier, 2015), thus may be beneficial in employment settings also. Increasing tolerance to uncertainty is linked to perceived locus of control and choice (Song & Li, 2017).

Theme 3: Sense of Control; Sub-theme 2: Occupational Autonomy

Occupational autonomy is the sense of control PwMS have in their workplace, for example, in decision-making around reasonable adjustments and the decision to leave work. Autonomy is a core component to self-determination (Deci, Connell, & Ryan, 1989; Deci & Ryan, 2008).

Having an increased sense of autonomy is positively linked to wellbeing and internal locus of control ((Wu, Griffin, & Parker, 2015(Wu, Griffin, & Parker, 2015). Internal locus of control has positive implications for job satisfaction, motivation, mental wellbeing, coping and health perceptions (Ng, Sorensen, & Eby, 2006). Contrarily, a low sense of control (or external locus) has negative implications for motivation (Bandura, 1982). Therefore, occupational autonomy may result in higher motivation to continue working, and increased wellbeing at work. Further autonomy may be an important job resource. As per the JD-R model (Bakker & Demerouti, 2007), increasing job resources can counter the negative impacts of job demands, therefore aiding job retention.

That said, McDonald and Harrison (2004) found that introducing a discourse of autonomy can lead to demoralisation and frustration, due to the additional pressures and time demands on individuals who are expected to make discretionary decisions within the confines of organisational-level values. Further, Van Yperen, Wörtler, and De Jonge (2016) found that increasing occupational autonomy was only motivational to individuals who felt a higher need for autonomy and perceived that blended working styles (for example, the ability to work from home) as an effective work strategy. Indeed, for some, the opportunity for blended working can have a negative impact on work and motivation (Van Yperen, Rietzschel, & De Jonge, 2014).

Finally, Langfred and Rockmann (2016) point out that despite the increasing demand for autonomy in job characteristics, organisations may be faced with navigational tensions between offering desirable job characteristics such as autonomy and retaining some level of bureaucratic control in order to operate efficiently and reliably. Langfred and Rockmann (2016) point out that "*the theories surrounding what happens when organizations grant autonomy have ignored the fact that hierarchical organizations are not inherently designed to handle the uncertainty involved in relinquishing control*" (p.636). Thus, while occupational autonomy can offer psychological benefits at individual level, this must be balanced with the potential tensions it creates which may result in higher-stress situations.

Britt, Crane, Hodson, and Adler (2016) found that acceptance of demands may offer an effective coping buffer to stress-factors in low autonomy work, while denial had negative consequences for mental health in such settings. Thus, in settings where increased autonomy may not be feasible, acceptance may offer a positive coping strategy that facilitates continued work stability.

Both-Nwabuwe, Lips-Wiersma, Dijkstra, and Beersma (2020) propose that autonomy at work has three distinct types: professional autonomy, individual task-based and group task-based autonomy. While professional autonomy refers to discretion based on specific job-related skills and knowledge (for example, a nurse making treatment decisions regarding a patient), the task-based autonomies reflect general organisational decision-making, such as working hours. Further, Both-Nwabuwe et al. (2020) consider that these different types of autonomy may have different implications for work-related outcomes related to various dimensions of meaningful work.

Lips-Wiersma and Wright (2012) developed a model to outline the dimensions of the concept of 'meaningful work'. The 'map of meaning' displays four core dimensions of meaningful work: *integrity with self, unity with others, service to others* and *expressing full potential*.

Interestingly, these themes can all be recognised in the present analyses. Integrity with self is consummate to authenticity at work (Chapter 5) as well as themes relevant to validation (e.g., *In/validation*, core model). Unity with others reflects multiple dimensions of the social relationships theme in Chapter 5 as well as the *Togetherness* theme in Chapter 4. Indeed, it can also be compared with the core model theme of *Social relations at work*. Service to others can be seen in the sub-theme *Responsibility to others* (Chapter 5) and expressing full potential is comparable *to Constructing social value* (core model) as well as the social value dimensions of Chapter 4. Recognising these areas that may contribute to meaningful work is helpful to aid job retention for PwMS, as meaningful work is linked with employee and organisational health (Di Fabio, 2017). Further, Di Fabio (2017) argues that the concept of meaningful work goes beyond motivation and goal-orientated behaviours; meaningful work and meaningful living is key to sustainability, growth, health, and success both at individual and organisational level.

Theme 4: Social Relations at Work (meso)

Interpersonal interactions in the workplace have a meaningful impact on how PwMS experience managing their MS at work, as well as the process of retirement.

Social relations at work sit at two distinct but interrelated levels: the employee-employer relationship, which is between the individual and the organisation, and the individual-co-worker relationship. Although these two distinct relationship types can be separated plausibly, disentangling aspects of interpersonal interaction that embody either the relationship with the co-worker on an individual basis versus as a representative of the organisation can be challenging. (Schalk & Rousseau, 2001) consider the recent shifts in these employment exchange relationships, which are happening globally. As demand for job characteristics move toward increased levels of flexibility, autonomy and negotiability, implicit agreements in the employment relationship are also shifting. Depending on context, this can offer some benefits to employees (e.g., increased autonomy, empowerment), but also increase certain risk factors to either party (e.g., power shifts, reduced protections).

It is important to help PwMS manage their psychosocial relationship with their occupational setting as disempowerment and validation are key considerations of those who have recently left work and may be crucial indicators of work-related outcomes. Encouraging empowerment and validation at work might be a joint responsibility but where it is challenging to engage employers, helping individuals with MS to manage their own feelings of empowerment and validation may offer suitable benefits.

Sense of community at work may be suggestive of a broader organisational climate that encourages psychological safety; psychological safety has important implications for interpersonal trust, empowerment and ultimately employee wellbeing (Kirk-Brown & Van Dijk, 2014). Psychological safety also mediates the relationship between job resources and affective commitment for people who are chronically ill, further demonstrating the importance of organisational culture in work stability for PwMS (Kirk-Brown & Van Dijk, 2016).

Social exchange theory offers a good explanation for how PwMS perceive their occupational environment (Cropanzano & Mitchell, 2016; Emerson, 1976). For example, where social exchanges are evenly balanced, PwMS are more likely to have better experiences; however, for PwMS, fragility of the social exchange may be increased as a result of their condition. Invisible illnesses have implications for social exchanges, such as an expectation to divulge personal information in order to counteract invalidation experiences. Further, social hierarchy influences social exchange, with morality featuring as a social norm of the employee-employer dynamic. This adds further complexity to the social dynamics PwMS are trying to navigate, sometimes at odds with their own needs.

Expectations of reciprocity can serve to strengthen interpersonal dynamics; where an employee sees that their efforts are reciprocated aptly, this can proceed to further positive social exchanges. On the other hand, PwMS may feel either that they cannot reciprocate resources provided to them, or that they must dedicate more effort to achieve the same level of work as their non-MS counterparts (or even their pre-diagnosis self). Thus, organisational-level interventions which focus on improving interpersonal relations and social exchange dynamics may be beneficial not only to the employee with MS, but to encouraging a motivated, committed workforce for the organisation.

Theme 4: Social Relations at Work; Sub-theme 1: Interpersonal Responses

This analysis, as well as examples from other literature, suggests that interpersonal responses to disclosure of MS in the workplace can follow one of two polarised responses: avoidance or over-engagement (Kirk-Brown & Van Dijk, 2014). This is usually due to how others cope with difficult topics. Disclosure of MS involves sharing personal information and has implications regarding social exchange theory. Social exchange theory posits that social exchanges need to be balanced (Emerson, 1976); therefore, when an individual with MS shares their diagnosis, this presents a sudden shift in the social dynamic. The individual with MS has provided a significant piece of personal information and the implicit socially perceived expectation is that the other party will now provide an equal exchange. However, as this is not usually feasible, the other party will feel uncomfortable and avoid the situation, or they will become paternalistic in an attempt to provide an equal exchange (through ‘caring’ duties).

Theme 4: Social Relations at Work; Sub-theme 2: Interpersonal Trust

Further to the mismatch in the social exchange, this analysis raised the importance of interpersonal trust for PwMS in the workplace. Rousseau (2001) theorised that trust is developed as a set of implicit expectations about reciprocal obligations between individuals. Where individuals with MS are already experiencing a sense of disparity in the reciprocity of the social exchange, this can create additional dilemmas. Analysis from previous chapters identified that PwMS feel that disclosure is an obligation related to honesty and trust. However, where there is a low sense of trust with an employer, this presents social complexities.

Feeling a sense of trust toward an employer representative, whether that be a direct manager, a higher manager or even a colleague, increased the sense of psychological safety for PwMS in the workplace setting. This created a support foundation from which the individual can build their sense of confidence to seek further support or request adjustments. The additional reassurance of stronger trust relationships has a positive effect on sense of predictability and somatic experience of chronic illness (Cohen & Wills, 1985; Kirk-Brown & Van Dijk, 2014). Further, interpersonal trust relationships can be beneficial for improving negotiations, social capital and career outcomes (Seibert, Kraimer, & Liden, 2001; Zaheer, McEvily, & Perrone, 1998).

Piccoli and Ives (2003) found that low autonomy organisational settings, such as teams experiencing higher levels of behaviour control, also tend to display lower levels of trust within the work team. This is suspected to be due to higher vigilance in identifying team-mates deviation from conformity within the organisational principles. As occupational autonomy is identified as a contributory factor to work outcomes for PwMS in the present analysis, the benefits of interventions that focus on increasing sense of autonomy may then be two-fold: improving outcomes relevant to sense of control and increasing interpersonal trust.

Theme 5: Constructing Social Value (micro)

Social value and paid employment are implicitly linked in capitalist society (Foster, 2007). In chapter 4, the concept of the ‘ideal worker’ was discussed. PwMS may find that the social value attained through paid work fluctuates depending on how well they are able to manage their condition at work. Social value, in the Western world, is linked to occupational identity (Unruh, 2004); occupational identity fulfilment is associated with wellbeing (Kielhofner, 2002).

Social value acquired through paid work may be related to core self-evaluation (CSE). Core self-evaluation encompasses “*fundamental appraisals that people make of their own self-worth, competence, and capabilities*” (Chang, Ferris, Johnson, Rosen, & Tan, 2011, p. 82), p. 82). CSE is determined according to self-appraisals about particular traits, how fundamental those traits are to the self and whether the trait is observed by the self as broad or domain specific. Traits associated with CSE include self-esteem, self-efficacy, and locus of control. CSE has been linked to job satisfaction, organisational commitment, motivation, performance, and reduced job strain (Chang et al., 2011). CSE outcomes might be explained by an approach/avoidance framework by which human experience can be characterised as either approach toward positive stimuli or avoidance of negative stimuli (Chang et al., 2011). This framework is mirrored in Higgins’ (1998) regulatory focus theory by which individuals may be promotion-focused or prevention-focused in their behaviours. Brockner and Higgins (2001) found that regulatory focus itself is not a predictor of work outcomes, but organisational fit may be important. That is, where an individual is promotion-focused and the organisational incentives are also promotion-based, work performance will be better; likewise, prevention-focused individuals perform better in work settings that use prevention-focused incentives. Current macro-level structures in the UK appear geared toward a prevention-focused approach; that is, work adjustments and support are focused on avoidance of loss rather than acquiring opportunities for growth.

In addition, social norms around work and retirement are important to consider how well PwMS adapt to leaving work; retirement that is not in line with expected norms may have negative implications for how health is experienced following retirement (Moen, 1996).

Norms and expectations can also influence how PwMS feel about their work outcomes. Psychological adjustment strategies to deal with goal adjustment and redefining success may be useful in helping PwMS cope with not meeting previous expectations related to employment (Barlow, Wrosch, & McGrath, 2020).

Theme 5: Constructing Social Value; Sub-theme 1: Realising Social Roles

The first “step” in constructing social value is realising social roles to which one identifies with. PwMS may face changes, or even threats, to their sense of identity through social roles. For example, some may consider an adjusted role of ‘disabled’ as part of their self-identity. Alternately, self-identity and social identity may not correlate. Social roles such as those imposed on the chronically ill require additional navigation. For PwMS in particular, the invisibility of symptoms contradicts social perceptions of the disability label, which they may need to adopt in order to obtain employment support (Valeras, 2010). Further, PwMS may struggle to uphold a previous social identity in order to avoid negative stigmas attached to illness and disability (Fitzgerald & Paterson, 1995).

Individuals may identify with multiple social roles, and at different yet distinct levels (Johnson, Chang, & Yang, 2010); collective level self-identities are those related to group memberships (Brewer & Gardner, 1996). This includes organisational membership, or occupational identity. Self-worth can be intrinsically tied to collective identity and the ability to fulfil group goals, norms and roles (Johnson et al., 2010). For PwMS, this can present an internal discord if they are no longer able to adhere to previous roles associated with a collective self-identity. Here, adaptive identity reconstruction is important and interventions that promote positive adjustment may be beneficial (Jakobsen (2009). In chapter 4, PwMS reflected on collective identities such as their class identity; reaffirming their continued membership of such collective identities can be a useful coping mechanism in response to identity threats or during identity reconstruction.

Theme 5: Constructing Social Value; Sub-theme 2: Value through Social Exchange

Although *Value through social exchange* is present for all individuals (MS or not) and will already be present prior to MS onset, how it occurs may shift following reassessment or reinforcement of social roles. This shift can have consequences for the in/validation process, as discussed above. Achieving value through social exchange can be an important aspect of the employment experience. PwMS in this study highlighted the importance of social connection, and the major role the workplace played in providing this. PwMS who have left work will benefit from finding alternative sources of value through social exchanges.

Theme 5: Constructing Social Value; Sub-theme 3: Accomplishing Norms of Social Value

Accomplishing norms of social value is context specific – in the UK, social norms around work may be different to other cultures. For PwMS in the UK, the ability to conform to cultural norms can influence psychological adjustment to work outcomes. These norms can include concepts of a ‘normal’ retirement age, patterns of working hours, time spent at work, productivity at work, organisational commitment, how and where work is completed, modes of communication and so on. The most discussed norms in this study related to the ‘ideal worker’ concept and expectations of retirement age. Expectations around retirement age are of course linked to national structures of social welfare, i.e., minimum age requirements for accessing state pension. For some PwMS, these age restrictions are lifted in place of retirement on medical grounds, or early retirement. There are different options around retirement with differing financial implications; for example, ‘early retirement’ is generally viewed as an opted-for premature retirement which may result in decreased state pension funding but might be taken if private pension funds are available and medical retirement cannot be granted. Medical retirement requires a stringent application process and is awarded based on individual assessment; this kind of retirement allows individuals with medically documented barriers to work to access their social pension without age restriction. However, medical retirement is conditional in that the individual must not continue to earn above a certain threshold through paid employment. If an individual’s condition improves and they decide to return to work, the pension payments will be stopped; for individuals on a higher bracket of medical pension payments, there is a risk of losing this indefinitely.

Theoretical Implications for Managing MS and Work

This core model brings together key concepts from the previous models developed throughout this thesis.

Knowledge management plays a decisive role in resource acquisition and empowerment processes for PwMS. Previous literature highlights the crucial role of social capital in knowledge management (e.g., Hall & Widén-Wulff, 2008) and the data in this present study supports this concept. PwMS with strong social ties in the workplace appear to have more positive work experiences. That said, exchange processes within the workplace may be less useful in explaining the experience of exiting work. This may indicate a shift in exchange networks; PwMS move from the intra-organisational exchange relationship to a wider cultural exchange dynamic. Individual resources will serve as a key indicator for the experiences of PwMS leaving work; those with strong resources (be that material or social) will likely have a more positive experience due to the transactional opportunities this presents.

In line with social exchange theory, societal organisation has developed implicit expectations and attitudes which serve to benefit wider social functioning (Trivers, 1971). However, it seems that people with disabilities have been left behind somewhat. Social constructs of disability appear to have been conflated in UK culture with moral norms (Lavery, 2017), meaning that people with disabilities are at risk of generalised negative reciprocations to their condition. Further, the invisibility of MS creates a discord with social norms of disability (Valeras, 2010), for which PwMS may be stigmatised, entering into a negative social exchange dynamic.

On the other hand, PwMS who are able to enter into empowerment processes may be able to circumvent this negative exchange dynamic at least at an interpersonal or intra-organisational level. Kirk-Brown and Van Dijk's (2014) empowerment model can be considered in conjunction with social exchange theory. The empowerment model distinguishes employer response to disclosure as either ability- or disability-focused, further delineating disability-focused responses to discriminatory and paternalistic. Ability-focused responses represent a positive social exchange, by which the employer recognises the beneficial resources an employee can offer and reciprocates with resources such as support. Disability-focused responses reflect negative social exchanges, although paternalism offers a complex mix with social support. This explains how paternalistic responses may result in a slightly obscure dynamic whereby PwMS experience job security but with low work efficacy.

Further, trust relationships appear to have an important part to play in how social exchange relationships develop. Rousseau (2001) defines trust as an implicit set of expectations and reciprocal obligations between two parties, thus aligning it with the core principles of social exchange theory. Although Connelly et al., (2015) explore the role of integrity-based trust in the organisational exchange dynamic, it would be interesting to explore further the role of *internal* integrity-based trust perceptions. Integrity with self, alongside unity with others and service to others, form key dimensions of meaningful work (Lips-Wiersma & Wright, 2012), which may influence sense of control, validation, and authenticity at work. Therefore, integrity with self may be a positive indicator for development of strong social ties in the workplace.

The core principle of resource exchange in social exchange theory is especially applicable when considered alongside the Job-Demands Resources model (JD-R; Bakker & Demerouti, 2007). A central tenet of social exchange theory is that social interactions rely on a cost-benefit analysis (Emerson, 1976). The JD-R model also includes the key principle of balancing resource and demand. Thus, the JD-R model suggests an explicit framework of social exchange processes in the specific context of work. The present study gives further evidence for how this occurs in the context of a chronic, invisible illness such as MS.

Although social exchange theory is useful to understand phenomena related to PwMS managing work, previous criticisms suggest this theory is limited to *post hoc* analysis (Cropanzano & Mitchell, 2016). However, Cropanzano, Anthony, Daniels and Hall (2017) argue that moving away from previous unidimensional approaches to social exchange theory and extending the model to consider activity (that is, active reciprocal action as distinct from inaction), better predictions can be made to support relevant interventions.

Practical Implications for Managing MS and Work

The core model outlines five key themes relevant to facilitating or hindering continued paid work for PwMS; *In/validation, Adjustment demands, Sense of control, Social relations at work,* and *Constructing social value*. The key themes identified in this analysis should help to signpost appropriate areas for intervention. Further, having the benefit of insight from a range of actors relevant to managing paid work with MS, this research can offer useful information about the wider social context that may influence work outcomes.

Levels of Intervention (Macro-, Meso-, Micro-level):

Prior to considering the interventions which may play a role in reducing barriers to paid work for PwMS, it is important to understand how these interventions might look, who they can be targeted to and the level of impact they might present. The multi-level approach of this study has provided evidence that interventions may be relevant at micro-, meso- and macro-levels. Therefore, it is important to consider how interventions might operate at each of these levels.

The figure below sets out the three key levels at which interventions may be targeted, including some brief examples.

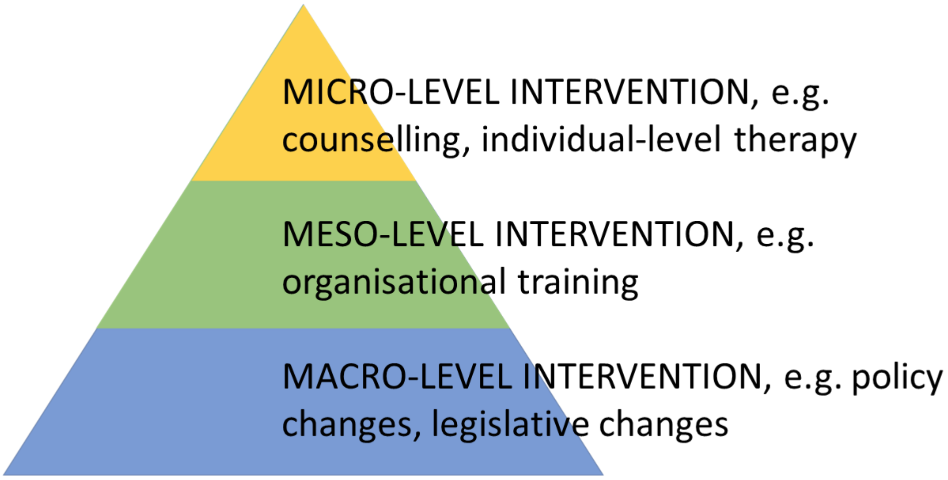

Figure 7.3 - Target levels for Intervention

Despite the simple appearance of this model, there can be a multitude of approaches at each level, with various advantages and disadvantages. The following paragraphs explore how interventions can be implemented at the three key levels.

Veinot et al. (2019) argue that interventions which are focused at the individual (micro) level may be limited in their reach and effectiveness, particularly for marginalised groups. Meso- and macro-level interventions offer the benefit that they can target greater numbers and multiple health outcomes. Despite this, a systematic review by Stowell et al. (2018) identified that the majority of interventions are targeted at individual level and informed by psychosocial theories. Thus, shifting focus of interventions to the context under which health inequalities occur may promote more effective change.

Macro-level Interventions

Rothman (2007) explores the range of approaches to intervention at macro-level. The work outlines three basic approaches: ‘planning and policy’, ‘community capacity development’ and ‘social advocacy’. ‘Planning and policy’ deals with data-led knowledge in order to provide rationalist reasoning for change and intervention strategies. ‘Community capacity development’ describes methods through engagement and empowerment of those affected directly by the intervention, and ‘social advocacy’ incorporates social justice activities to apply social pressure and push for change. We can see that these three levels of approach are analogous to the epistemological frameworks that critical realism stems from: the objective, realist stance of ‘planning and policy’, the subjective, empirical notions of ‘social advocacy’ and the combined critical approach as ‘community capacity planning’.

Further, Rothman (2007) outlines how combinations of these basic approaches can form nine distinct modes of intervention. While ‘planning and policy’ dominant approaches offer rational and empirically supported methods, these top-down approaches are limited in that marginalised groups for which they may offer intervention are not consulted. Thus, outsider assumptions may miss less tangible but important details that the insider experiences. On the other hand, ‘social advocacy’ requires a ‘bottom-up’ approach that often sees those marginalised groups utilise ‘people power’ (as one of the few powers they can access) to demand change and reformation.

‘Community capacity development’ focused methods appear to offer a useful initiative for PwMS to improve their work outcomes. Specifically, the capacity development strategy is “*the empowerment of people and communities– energizing them to act competently on their own behalf in determining goals and taking civic action.*” Rothman (2007, p. 22). In other literature, this is sometimes referred to as community development or social development, although Rothman points out the limitations that these terms can become confused with alternate connotations, notably community development referring to economic urban planning.

The ‘community capacity development’ approach is incredibly person-centred, in that it empowers individuals and groups so that they can help themselves in a way that is consonant with their own needs (Rothman, 2007). Despite early critique of community development work as a ‘soft’ strategy leading to inaction (e.g., Khinduka, 1987), literature has pushed forward with the benefits of this approach, particularly in social work. Moreover, Brady and O’Connor (2014) outline a formal practice theory that helps to combat the potential risk for inaction.

However, Langfred and Rockmann (2016) argue that organisations have an inherent need to maintain some level of control in order to facilitate structure and coordination, which forms the original core of organisations. At present, organisations are caught between managing this need to maintain control with the increasing demand for employee autonomy at work. Further, activity which may contribute to increased efficiency in the traditional workplace (e.g., standardised procedures) directly oppose features of autonomy such as individual discretion, creating further complexities in navigating suitable outcomes for both the individual and the organisation. Langfred and Rockmann (2016) argue that the increased stress of such tensions for managers may lead to reduced tolerance to uncertainty, which in turn trickles down to employees. In the case of MS, a condition inherent with uncertainty, this is likely to have negative consequences.

Thus, macro-level interventions aimed at empowering PwMS to take action against workplace inequalities may face resistance where the needs of PwMS are at opposition to conventional needs of an organisation.

Meso-level Interventions

Meso-level interventions have been referred to in the literature as organisational development or knowledge management. Buljac-Samardzic, Doekhie, and van Wijngaarden (2020) provide a systematic review on team-level interventions in healthcare occupational settings, and outline three types of intervention: training, tools, organizational (re)design or a combined programme of all three. Their review suggests that training is the most commonly investigated and may be the most effective. Training can focus on predefined principles, a specific method or general team training. Tools are used to structure, facilitate or trigger team interaction and organisational (re)design involves a broader shift in responsibilities and roles. However, many of these interventions and the outcomes measured alongside them are based in behaviour rather than knowledge. A review by O'Dea, O'Connor, and Keogh (2014) did establish that a specific type of training (Crew Resource Management; CRM) could contribute to improved knowledge in teams in acute healthcare settings. O'Dea et al. (2014) note that the focus of CRM is “*not on technical skills but rather cognitive and interpersonal skills, such as* *communication, situational awareness, problem solving, decision making, leadership, assertiveness and teamwork.”.* Training of this nature may be translatable to reducing stigmatisation or invalidation and improving empowerment of PwMS at work. The present study highlighted that knowledge congruence plays a key role in social barriers to work for PwMS. Meso-level interventions that focus on improving workplace outcomes for PwMS would likely require a change focus on knowledge rather than behaviour, in order to be effective.

Meso-level interventions which focus on increasing job resources to combat high job demands may also be beneficial (Spoor, de Jonge, & Hamers, 2010). The current study saw that PwMS may experience additional job demands due to symptom management, social barriers and psychological impact related to MS. Thus, increasing job resources throughout an organisation such as autonomy may reduce the negative effects of these demands.

Micro-level Interventions

Micro-interventions refer to those which focus on individual level factors, such as psychological states. Luthans, Avey, Avolio, Norman, and Combs (2006) coin the term psychological capital (or PsyCap) which refers to a positive psychological state comprising self-efficacy, optimism, hope and resilience. Luthans et al. (2006) argue that the combination of these psychological factors is not only beneficial to developing the ideal self but produce a synergistic effect greater than the sum of its parts. Psychological capital can be useful in relation to improving work outcomes. Indeed, work outcomes have been shown to be linked to the respective states of self-efficacy (Ford, Wicks, Stroud, & Tennant, 2019), optimism (Kronstrom et al., 2011), hope (Reichard, Avey, Lopez, & Dollwet, 2013), and resilience (Caza & Milton, 2012).

Previous literature has identified interventions that focus on psychological states and work; for example, stress (Niks, de Jonge, Gevers, & Houtman, 2018) and self-efficacy (Jongen et al., 2014).

McGonagle, Beatty, and Joffe (2014) found that interventions which looked to increase internal resources such as self-efficacy, core self-evaluations and job satisfaction were beneficial in countering the negative impact of job strains.

Individual level interventions can also focus on physical, functional, or cognitive factors. A review by Tur (2016) highlights interventions aimed at reducing fatigue.

However, Lloyd, Bond, and Flaxman (2017) drive home that interventions do need to consider person-level moderators; for example, in their ACT-focused intervention study there was a notable effect of intrinsic work motivation, such that employees with low self-efficacy and low motivation actually experienced adverse outcomes compared with their highly motivated counterparts. Thus, understanding individual-level factors that may impact intervention success is important.

Therefore, in addition to level of application, intervention strategies must consider and assess the relative need and impact of intervention. The next section explores how current literature has addressed this in various settings and considers how this might be applied to reducing barriers to continuing work for PwMS.

Fisher and Purcal (2016) review how targeted policies at micro-, meso-, and macro-levels can influence attitudes and reduce stigmatisation of people with disabilities. Fisher and Purcal (2016) consider how wider policies such as access to appropriate healthcare can have a positive effect on reducing social barriers for people with disabilities.

Intensity of Intervention/Intervention Pathways

Hutchison, Steginga, and Dunn (2006) propose a tiered approach to oncological care services, using psychological distress levels to determine which tier of intervention (ranging from generic, broad information sharing to acute, specialist therapies) an individual might benefit from. Utilising a triage system to assess psychological distress, this framework allows oncological care teams to direct patients to interventions most appropriate to their individual need. This is highly feasible at the micro-level and tools such as the Work Instability scale (McFadden et al., 2012) are ideally placed for determining individual need for intervention strategy. However, at the macro- and meso-levels, identification may not be as clear-cut.

Reed and Vakola (2006) investigated a training needs analysis for determining organisational development needs. Using action research methods, which Schein (1999) argues are imperative in any change management, Reed and Vakola (2006) found that a significant barrier to developing strategies for change management is managing the cultural and change issues that arise. They attribute some of these difficulties to inherent organisational culture that stems from bureaucratic practices.

Bolden (2010) points out that organisational change is interdependent with leadership and management processes. Thus, leadership and management development should consider desired outcomes of wider organisational change. Bolden goes on to outline a useful framework for leadership development, which reflects key aspects of action research: participatory involvement, joint-development and reflective learning and evaluation. Action research has been evidenced as a useful method for implementing appropriate change processes at organisational level; McAnaney and Williams (2012) illustrated that the participatory nature of action research methods can aid positive change and lead to reduced stigma in disability management.

In the educational setting, (Mellard, 2009) describes a 3-tier pyramid for intervention according to requirements: *primary* covering broad, standard teaching sessions, through to *tertiary* for students who need individualised tutoring; as the intervention strategy moves toward tertiary methods, intensity and frequency is seen to increase and the recipient group size reduces. Mellard’s (2009) model is based on the concept of a multi-tiered system of support and the response-to-intervention programmes which are utilized across the schooling systems of the US (Choi, McCart, & Sailor, 2018; Sugai & Horner, 2009).

On a macro-level perspective, Frieden (2010) suggests a 5-tier impact pyramid for public health action (Figure 7.4). The framework shows the different points at which intervention can occur, and the corresponding individual effort required versus population impact (arrows either side).

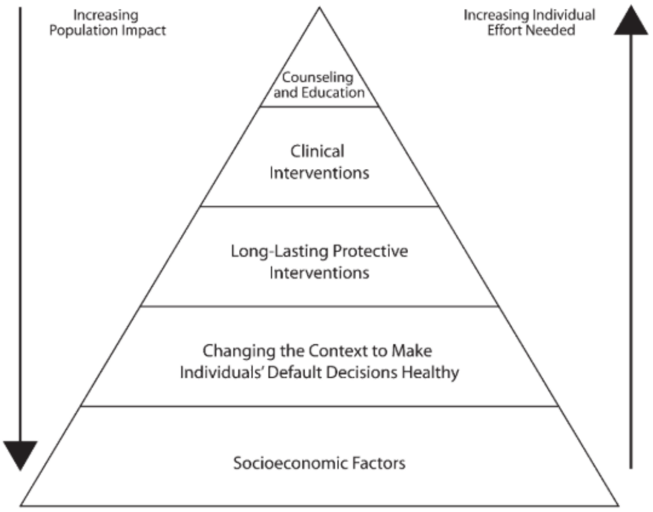

Figure 7.4 - A 5-tier health impact pyramid (Frieden, 2010)

Although placed at different levels of social organisation, and focused on various measurable outcomes, these models have core similarities. Interventions can range from broad, generic focus through to specialised, specific outcomes. Further, the higher intensity required for more specialised outcomes usually necessitate a smaller, focused, higher needs recipient group size.

These tiered approaches tend to focus directly on the population of emancipatory concern. However, analysis from the present study highlights the importance of promoting change in the wider context, such as cultural norms, public knowledge, and organisational knowledge management. Thus, for interventions at the meso- and macro-levels to be effectual, focus must include involvement of the wider community. In the context of PwMS in paid work, a tiered framework can be used to delineate intervention strategies as generic, themed, or specialised in their application. The pyramid below illustrates this simplified version.

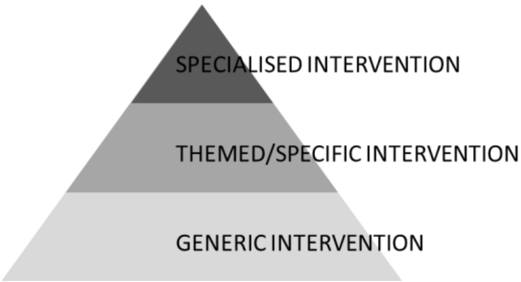

Figure 7.5 - A 3-tier intervention impact pyramid

‘*Generic*’ interventions are those often available to the wider public. These can include advertising or public service campaigns and accessible online content such as the MS Society information webpages. Generic interventions are focused on information sharing in order to equip the recipient with relevant knowledge aimed at improving various outcomes; for example, information leaflets related to work-related adjustment strategies can help toward improving workplace outcomes for PwMS.

‘*Themed/Specific’* interventions include training programmes that an individual or group may be able to access by self-referral, but are specific to individuals, groups or organisation looking at implementing a specific change or outcome. Training programmes and educational courses fall into this category, as do dedicated support groups for PwMS.

‘*Specialised*’ interventions are those targeted at specific individuals or groups and which require professional referrals following identification of acute support needs. This includes therapeutic courses and vocational rehabilitation programmes. Such interventions are often administered by specialists in a relevant field, such as clinical psychologists.

Combined Model of Intervention Approach

Finally, if we combine these two models to consider interventions at the micro-, meso- and macro- levels, in addition to the needs-based intensity levels of intervention, we can see that there are nine distinct levels for intervention relevant to addressing social problems, such as barriers to work for PwMS. This is shown in Figure 7.6 below, with examples provided in Table 7.1.

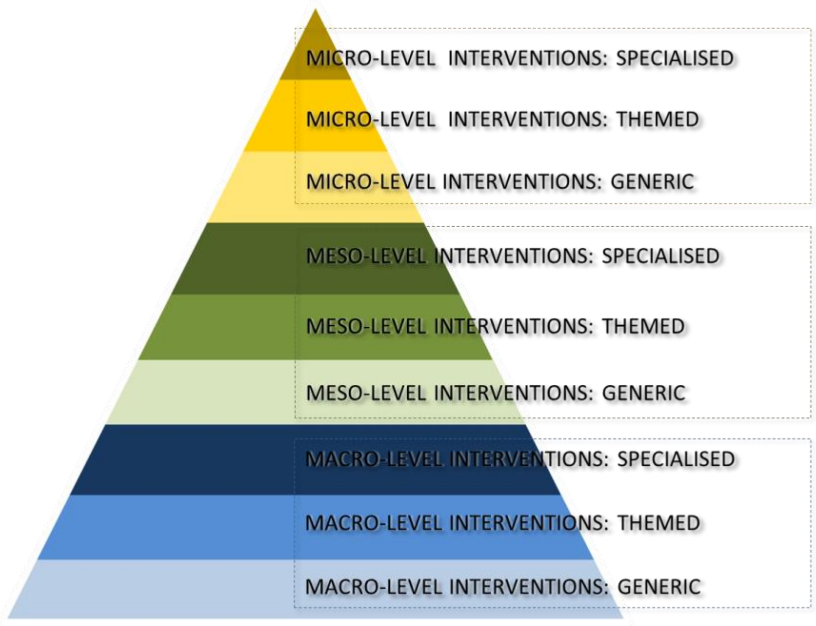

Figure 7.6 - Tiered multi-level pyramid of intervention approaches

Table 7.1 - Tiered multi-level interventions with examples

Micro-level: Generic interventions	**Generic individual-level interventions may include providing leaflets and information to people newly diagnosed with MS.**
Micro-level: Themed interventions	Themed interventions are the individual level include attending relevant support groups
Micro-level: Specialised interventions	Specialised interventions are those such as strategic psychological therapies, occupational therapy support or vocational rehabilitation.
Meso-level: Generic interventions	At organisational level, generic interventions may simply include mailing list announcements to promote new or existing values.
Meso-level: Themed interventions	Most meso-level interventions in the literature will fall into the themed interventions category. These include organisation development and knowledge management strategies to promote general employee wellbeing, job satisfaction and work productivity.
Meso-level: Specialised interventions	Meso-level specialised interventions may occur following a needs-based analysis or using a participatory action research approach. Development of forums for marginalised groups can be used to identify where inequalities exist; specific training can then be provided to managers or across the organisation in order to reduce these inequalities.
Macro-level: Generic interventions	Broad form interventions, targeted at a wider populate/public, e.g., publicly placed information posters, television commercials, normalisation of marginalised groups through representation in the media. Although Fisher and Purcal (2016) posit that awareness campaigns and positive media portrayal of marginalised groups are person-level interventions in that they attempt to change the attitudes of individuals, the delivery of such interventions can be utilised on a macro-scale.
Macro-level: Themed interventions	Themed macro-level interventions might involve social advocacy campaigns focused on making specific improvements. Rothman's 'community development planning' encompasses this. An example of a macro-level themed intervention might be an organised litter clean-up to tackle public waste issues, or 'the great get together', a national event organised to encourage community values in response to the murder of politician Jo Cox. Specific to MS, initiatives such as the MS Society all-party parliamentary group (APPG) can be useful in identifying and promoting action on relevant issues in parliamentary processes (e.g., Employment that works: Supporting people with MS in the workplace; All-Party Parliamentary Group for MS, 2016). Campaigns and calls for action by APPGs can lead on to specialised intervention strategies.
Macro-level: Specialised interventions	A relevant example of a macro-level specialised intervention strategy is of those taken during the COVID-19 global pandemic; on a macro-scale, interventions must be enforced and at a higher intensity than public service announcements. Policy changes and new legislation has been passed at a priority rate.

Points for Intervention

Now that we have established some key tenets of intervention strategies, we can begin to focus on how this can be applied to the core model. The below figure illustrates points of intervention, as shown by the coloured stars. Micro-level interventions are shown in yellow, meso-level in green and macro-level in blue. The positioning of the stars also indicates at what temporal stage (e.g., ‘onset-to-diagnosis’) the PwMS may be at where this first becomes a relevant point for intervention. Note that intensity of intervention is not illustrated as this is determined on a case-basis and requires a process of triage that must be assessed discretely.

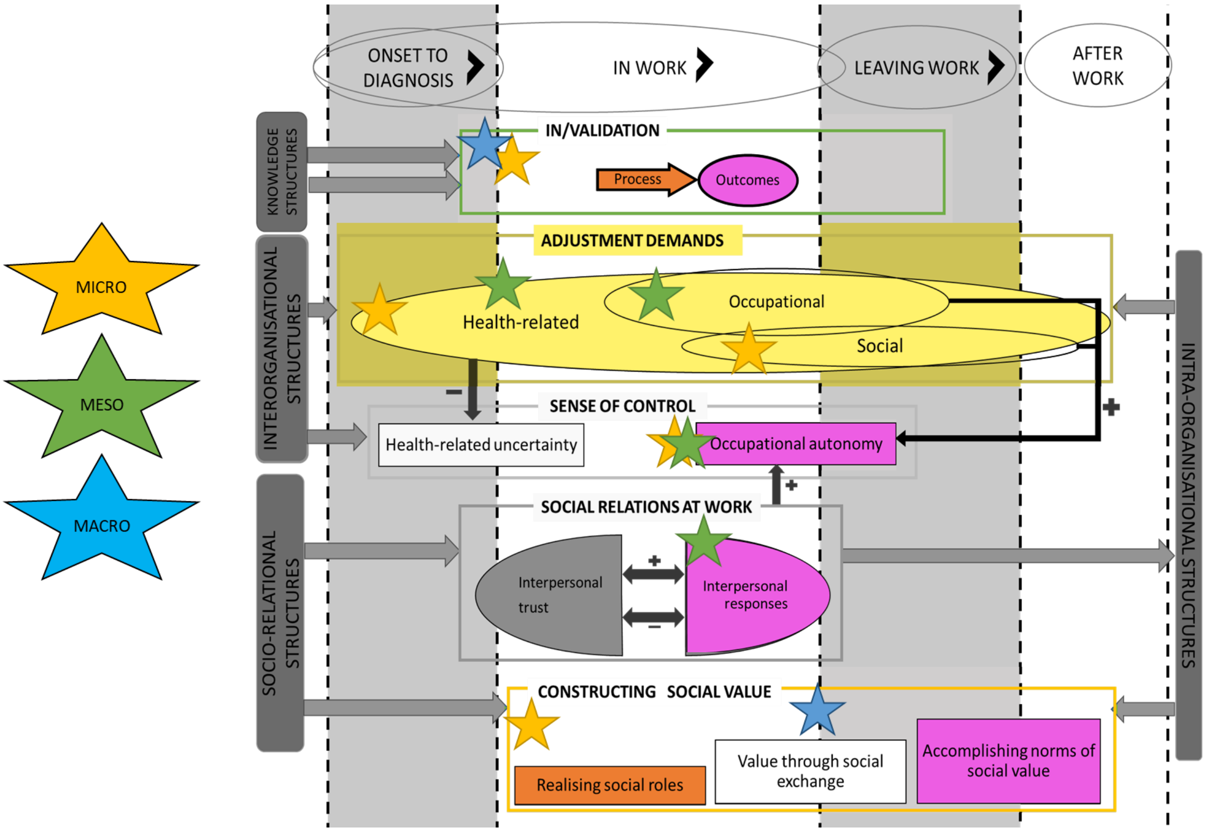

Figure 7.7 – Points for intervention (as indicated by stars)

In/validation

At the macro-level, invalidation often occurs through stigmatisation and is related to knowledge incongruence. Thus, macro-level interventions would be best placed to focus on knowledge management. Knowledge management strategies in occupational settings have been explored widely in the literature (e.g., Gold et al., 2015) although less so in response to reducing stigmatisation of marginalised groups.

Micro-level interventions might focus on coping with invalidation, improving self-validation and empowerment. Previous studies have looked at the buffering impact of self-efficacy and pain acceptance on impact of illness invalidation (Cameron et al., 2018); interventions such as Acceptance and Commitment Therapy (ACT) which focus on self-efficacy and acceptance therefore may be helpful to address invalidation (e.g., Lennox, O'Neill, & Hannigan, 2017).

Interventions focused on reducing invalidation or improving validation outcomes for PwMS in work are relevant at any time following onset of MS for PwMS in paid work. As chapter 1a highlighted, the processes of invalidation can begin from as early as onset of MS. The uncertainty and the often-times requirement to take time off work for diagnostic tests or symptom onset can be a precursor to a divergence in knowledge between PwMS and their co-workers.

Adjustment Demands: Health-related

Opportunity for health-related adjustment strategies on an individual-level begin from onset. Information and literature available related to symptom management is generally extensive (Beer, Khan, & Kesselring, 2012), although the individualistic nature of MS can still present a challenge to finding individually relevant strategies.

Although organisational commitment to diversity can be useful to promoting an inclusive setting in which health-related adjustment needs are met without obstacle, meso-level need for interventions are usually not detectable until after a diagnosis of MS becomes present in the workplace. Further, organisational development strategies may need to include participatory action research techniques in order to be effective; therefore, it is important that individuals with MS in the organisational community as well as their managerial co-workers are included in change management.

At the micro-level, strategies to manage individual symptom impact can be utilised, in addition to coping and acceptance therapies, and interventions related to stress-management.

Adjustment Demands: Occupational

Occupational adjustment-demands are subject to organisational-level intervention. Chapter 6 highlighted the role of organisational culture on capacity to support employee wellbeing and facilitate workplace adjustments. Thus, interventions aimed to address occupational adjustment demands should be geared toward organisational development, as well as skills and knowledge management.

In addition to promoting attitude and behaviour changes at organisational level, support systems in relation to financial and occupational planning would be beneficial to PwMS. Chapter 6 identifies gaps in support structures, policy frameworks and clear pathways when it came to making decisions around changes to employment (e.g., reducing hours, retirement). Occupational and social adjustment demands were also linked to occupational autonomy. Therefore, interventions might consider this relationship in more depth.

Adjustment Demands: Social

Although these generally occur as a consequence of societal-level or cultural norms, social adjustment demands should be addressed at the individual-level. This is not to say that cultural norms should not and cannot be challenged, but rather that emancipation from these kinds of expectations are less to do with a current lack of policies, but rather an individual-level relationship with self-validity. Therefore, interventions aimed at promoting positive social adjustment strategies would do best to focus on coping with goal-adjustment and transitions, self-identity and empowerment.

Occupational Autonomy

Occupational autonomy may be amenable to both meso-level and micro-level interventions. Meso-level interventions which utilise training programmes to increase overall sense of autonomy across an organisation can be beneficial. Alternately, individual-level interventions to increase sense of autonomy, particularly if an individual is working in a low-autonomy job that cannot be adapted, may be helpful. However, such interventions should be mindful of the impact of increased autonomy on social relations at work (e.g., McDonald & Harrison, 2004). Further, occupational autonomy that includes increased decision-making demands may serve to increase negative impact of occupational adjustment demands for PwMS who are already feeling burdened by managing their workplace adjustments without adequate support.

Interpersonal Responses

Interventions to improve interpersonal responses to an MS disclosure at work may be beneficial at the meso-level. Organisational training or organisational change programmes can be useful in helping employees and managers to manage conversations around MS and work, as well as support PwMS without risking further disempowerment. Organisational development interventions should consider the role of the social exchange (Emerson, 1976); empowering PwMS at work through social advocacy programmes may be valuable.

Constructing Social Value

Macro-level interventions are most appropriate for impacting social value outcomes. Promoting public shifts in social value perceptions and norms through policy change, legislation and public resources are all likely to be beneficial to reducing the negative impact current norms pose to PwMS. In lieu of policy changes, micro-level interventions which focus on positive self-identity, self-efficacy, goal adjustment and acceptance may be well-placed to improve work outcomes for PwMS.

Strengths and Limitations

This research uses a critical grounded theory (CGT) approach; therefore, the findings are data-led rather than informed by positivist enquiry.

Critical realism recognises that, whilst external truths may exist, our interaction with them influences the reality we experience (Oliver, 2011). Critical realism acknowledges elements of both the positivist realist stance (reality can exist external to human conscious) and the constructivist viewpoint (reality is defined by our meaning-making) while simultaneously rejecting the blinkered limitations of verification methods or the impracticality of naïve observation. Further, CGT recognises that the researcher is not simply a neutral spectator, but a participant of the wider social constructs of which she is scrutinising (Belfrage & Hauf, 2016). In doing so, the researcher is better placed to recognise and work to resolve social issues exposed by the research data.

The inclusion of a literature review offers strength to this research. Where previous iterations of grounded theory called for avoidance of a literature review in case of any preconceptions interfering with the data-led approach (Glaser & Strauss, 1967), CGT promotes an initial literature review. Robert Thornberg (2012) argues that the "*naïve empiricism fails to recognize the embeddedness of the researcher within an historical, ideological and socio-cultural context*" (p.246). Instead, the retroductive approach utilised in CGT encourages the researcher to continually and iteratively refine theories and conceptualisations, through cycles of analysis and literature evaluation in order to arrive at a comprehensive result that incorporates the present data and the contributions of previous research. In doing so, CGT resolves criticisms of the inductive approach inherent to previous iterations of grounded theory which limits the research to the cases it studies.

This analysis also offers the benefit of a multi-level insight, through inclusion of PwMS in work, PwMS who have left work and relevant professionals. This has allowed exploration of the research questions from multiple temporal viewpoints (i.e., during employment and post-employment) as well as input from individual-level and organisational-level representatives. Analysing perspectives of PwMS as well as those responsible for their management either at work or in the healthcare pathway allows the analysis to span the micro-, meso- and macro-levels by looking at the differences and similarities in these perspectives. Including multiple perspectives in this way allows for mechanisms to be seen that may otherwise have been missed. Further, critical realism is interested in the measurement of change to understand underlying mechanisms. While this project was subject to time-constraints, change can be tentatively measured through comparison of the perceptions of PwMS in work and those who have left paid work.

A further strength of the methodology is the use of semi-structured interviews to collect the raw data. The use of semi-structured interviews lends itself well to the CGT approach, in that it allows additional insights to be explored in the moment, led by the participant. The interview guides for this research study were informed by the systematic research review; this allowed the interviews to remain relevant to the research questions and explore and test early conceptualisations in more depth. The rigidity of structured interviews is contradictory to the retroductive approach of CGT, while unstructured interviews risk deviating from the social problem of interest.

For these reasons, having prior knowledge of MS through prior occupational roles has been a benefit to this work. As a researcher, this has allowed me to offer a wider engagement that I may not have been able to had I approached the research question as a naïve observer; for the CGT method, this is particularly useful. Further, existing network connections, knowledge-acquisition and informal conversations that have occurred as a result of a historical interest in this area have been assets to developing more comprehensive conceptualisations.

Finally, this PhD project is subject to the excellent guidance of two supervisors: one offering expertise in qualitative method, and the other with a clinical expertise in Multiple Sclerosis and both with established involvement in high-quality research.

While the concept of ‘theoretical saturation’ is an aim of grounded theory method, CGT posits that this is never truly attainable; knowledge production can never really be complete and conceptualisations are continually open to refinement, as is inherent to the retroductive process (Hauf, 2016). That said, the researcher can strive to explain the social problem relevant to a particular context and time-point. Despite knowledge and mechanisms being continually subject to change, this is not to say that research of this kind is not useful or meaningful. In seeking to understand and explain a given social problem, this can catalyse emancipatory processes and serve to offer insights to intervention strategies to this effect despite never being ‘theoretically complete’ (Hauf, 2016).

Throughout the course of the research project, the retroductive cycle of data collection and analysis provide opportunity to test and refine emergent theories. As the analysis develops further, a point is reached where major concepts cease to arise and the key themes can be summarised. Although continued analysis may produce more granular concepts, a balance must be established by which these mechanistic iterations are not sufficiently beneficial to the wider social problem under scrutiny. That said, due to limitations in recruitment, the data may not capture a complete picture for all stakeholders. The Employer data set provides only a limited scope of potential perspectives, with both participants stemming from public sector organisations. Several routes were explored to recruit employer representatives, with limited response. One private organisation initially agreed at the lower managerial level to participate, but this was later rescinded by higher-level managers; while it is only speculative, this might suggest some negative events the organisation did not wish to be made known. Further research is needed to explore the perspectives of private and charitable organisation representatives who may provide additional insights. Moreover, removing potential barriers to organisations sharing what they may consider ‘bad press’ needs to be addressed.

The researcher also notes that the data offers limited perspective from Black and Minority Ethnic (BAME) individuals. Although previous studies have shown an increased risk of MS in black women (Langer-Gould, Brara, Beaber & Zhang, 2013), unfortunately participants in this demographic group could not be identified for this study despite ongoing attempts. Bhopal and Deucher (2015) note that marginalised groups are less likely to participate in research. This can be due to power hierarchies, not just in social structures but within the research relationship itself. Contrarily, outsider research may offer an opportunity to challenge assumptions that can be difficult to disentangle from an insider perspective. Therefore, it is especially unfortunate that a key demographic representative could not be identified.

Bhopal (2010) argues that to simply include marginalised participants in research does not necessarily do enough to empower these groups. Researchers must pursue objectivity through reflexivity and a consideration of their own perceptions, to aid representation of the respondent's voice (that is not muddled with the researchers' own assumptions). Conventional recruitment methods, even those that utilise the internet, may not be sufficient to reach or encourage marginalised groups to participate in research. This highlights a major shortcoming in recruitment methods, that future research would do well to learn from. It may then be more valuable to encourage and empower marginalised groups to collaborate in research from the 'researcher side'; structural barriers to academia and the research process that impact BAME members must be consciously dismantled. Bell, Berry, Leopold and Nkomo (2021) provide a critical summary of the history of racial inequalities that continue to keep BAME members excluded from academia and research, asserting that "*Anti-racist allies must work from the position that anti-blackness and White supremacy are omnipresent in academia, assuming that, like air, they exist in some form in every criterion, classroom, editorial decision, interaction, and space, and people are standing by doing nothing to intervene*" (p.51). Thus, researchers must continually look for ways to move beyond their personal 'echo-chambers' whilst recognising and responding to concerns that marginalised groups or 'outsider' group members may hold.

It is worth noting that toward the end of this research project, the global COVID-19 pandemic has led to significant shifts in the employment setting for many workers, including PwMS. Although the majority of data were collected prior to this pandemic taking effect, the resulting impact of COVID-19 may well have led to novel mechanisms not identified from these analyses. However, I would argue that much of the learning from this work can offer transferable insights; for example, the concept of the validation processes that PwMS are subject to in the workplace are likely to persist, but with nuances. Many PwMS, alongside other employees with adjustment needs, who have previously been told that flexible working approaches are not feasible, are now finding that such flexible working styles are now not only possible, but essential. In this respect, these changing mechanisms may not be different in their kind, but rather in their intensity. Further, had this research been conducted following the COVID-19 pandemic, it will likely have identified some additional conceptualisations that were not present at the time of this data collection. Regardless of such a major event as a global pandemic, the CGT approach recognises that mechanisms and conceptualisation are continually open to change.

Future Work

This work has identified the core themes relevant to workplace barriers and facilitators for PwMS. The method of analysis has been fundamental in recognising that interventions should ideally be considered at multiple levels in order to facilitate meaningful change. Thus, future research should be aimed at identifying and assessing the multiple modes of intervention available, and how these can be utilised effectively to improve employment-related outcomes for PwMS. Although beyond the scope of this project, a systematic research review would be beneficial to identifying where there may be current gaps in intervention approaches at the macro- and meso-levels in particular. Further, this research highlights that further consideration should be paid to supporting PwMS in and after the retirement process; notably, this can be a vulnerable period of change in which PwMS find themselves navigating social adjustments and major shifts to self-identity. Access to appropriate support during this period may be beneficial.

Reflexive Considerations

Due to my personal conceptions about the benefits of working, I began this research with a mindset of hoping to reduce barriers to work so that PwMS can stay in work longer. I considered that work offers psychological and physical benefits to the individual, including those with chronic illness, which made staying in work a priority. I had not yet fully considered the role of social processes involved in the experience of paid work, and how these might impact work outcomes and the desire to stay in work. I perhaps conflated paid work with concepts such as ‘career’; within my own upbringing the construct of work has been entangled with career and progression. I also saw work as a core part of an individual’s identity. I felt that paid work needed to be meaningful.

I realised quite early on that leaving work may have its own benefits that staying in work cannot offer, and that staying in work longer may not be the preferred outcome for all PwMS. Further, I discovered that others may not frame work in the same way as I do; for some participants paid work could be meaningful outside of an associated identity or career. Despite my understanding that value can be attained outside of paid work (e.g., raising a family, volunteering), this study has highlighted the complex social processes involved in constructing and achieving social value.

I began this research with an internal narrative that PwMS embodied the “disabled protagonist”, or even victim, trying to stay in work against the antagonist, their MS. The employer embodied a secondary character whose role had a limited bearing on the work outcomes of PwMS, possibly the sidekick who can provide moral support and an additional perspective but does not dictate the quest. This appears not to be the case. The mechanisms of social exchange suggest that employer plays a very tangible and crucial role in how PwMS experience work, how they feel about staying in work against challenges, be those social or otherwise, and even how they experience leaving work.

Concluding Remarks

This project offers valuable insights to the key areas that may help or hinder PwMS who want to stay in work, as well as the wider contextual factors that influence positive and negative in-work and post-work experiences. Notably, this research identifies the complex social barriers that PwMS are faced with in the workplace, including invalidation processes, interpersonal relations and the role of social value. In addition to physical and psychological adjustments, PwMS may also have to manage social adjustments such as social identity alignment and major transitions such as early retirement planning. These are usually in addition to managing increased work demands, MS symptom fluctuations and psychological impact of uncertainty around MS and work.

The use of a critical grounded theory method offers a relevant means to exploring the social phenomena at hand.

How interventions around these themes could be successfully implemented at multiple levels, including meso- and macro-levels, should be explored, as a multi-level approach to reducing such barriers would offer more significant and longer-term benefit than any singular-level approach. The core model offers insight to the larger structures that influence barriers and facilitators to work outcomes for PwMS, including knowledge structures, and organisational factors. Thus, these are pertinent areas to consider in the pursuit of effective intervention strategies.

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Appendix A – Systematic Research Review

Appendix A.1 – Search Strategies

EBSCOHost

Term	EBSCOHost
(MM "Multiple Sclerosis+")	(51,043)
(MM "Employment+") OR (MH "Employment of Disabled+")	(56,761)
employ* OR unemploy* OR self-employ*	(771,835)
"reemployment"	(459)
(MM "Personnel Management+") OR (MH "Career Mobility+") OR (MH "Employee Performance Appraisal+") OR (MM "Job Re-Entry") OR (MH "Employer-Employee Relations+") OR (MM "Workload")	(195,795)
worksite OR workplace	(64,789)
absenteeism	(14,669)
career	(90,665)
return* W1 work	(13,425)
vocational W3 rehabilitation	(4,311)
access W1 work	(214)
sick* N3 leave	(11,112)
disab* N6 discrim*	(1,530)
organi?ational W3 culture	(29,584)
(early N1 retire*) OR (health N3 retire*)	(7,398)
(reasonable W2 adjustment) OR (workplace W2 adjustment)	(141)
jobseek*	(167)
(employment W1 support W1 allowance) OR (personal W1 independence W1 payment*)	(36)
(disability N2 benefit*) OR (disability N2 welfare)	(2,084)
corporat*	(193,426)
occupation* N3 adjustment	(6,848)
trial OR drug* OR imaging	(7,641,531)
multiple W1 sclerosis	(81,396)
S1 OR S23	(81,426)
S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21	(1,234,394)
S24 AND S25	(2,189)
S26 NOT S22	(1,482)
Limiters - Peer Reviewed	(329)
Narrow by Language: - english	

OVID

exp multiple sclerosis/	63341
"multiple sclerosis".mp.	85500
or/1-2	85500
(employ* or unemploy* or self-employ*).mp.	776078
reemployment.mp.	1475
(return* adj1 work).mp.	203
(worksite or workplace).mp.	73061
exp vocational rehabilitation/	16739
(vocational adj rehabilitation).mp.	8907
workplace intervention/ or exp employee assistance programs/ or exp human resource management/	51644
absenteeism.mp.	15328
"occupational adjustment".mp.	1925
exp working conditions/	25572
exp occupations/	40985
(access adj1 work).mp.	52
(organi?ational adj culture).mp.	21308
"accommodation (disabilities)"/	362
(reasonable adj adjustment*).mp.	145
jobseeker*.mp.	72
retirement/	12776
((early adj retirement) or (health adj2 retirement)).mp.	4691
"disability discrimination".mp.	593
social security/	8285
"Disability Living Allowance".mp.	47
"personal independence payment".mp.	4
corporat*.mp.	39633
(trial* or drug* or imaging).m_titl.	884849
or/4-26	972382
3 and 28	2098
29 not 27	1990
limit 30 to english language	1848
limit 31 to peer reviewed journal	1765
remove duplicates from 32	1440

Web of Science

Search ID	Hits	Term
1	105,822	TOPIC: (multiple sclerosis)
2	123,470	TOPIC: (employment)
3	1,197,943	TOPIC: (employ*)
4	42,919	TOPIC: (unemploy*)

5	4,495	TOPIC: (self-employ*)
6	590	TOPIC: (reemployment)
7	8,056	TOPIC: (return* near/1 work)
8	61,247	TOPIC: ((worksite) or (workplace))
9	5,950	TOPIC: (absenteeism)
10	93	TOPIC: ("occupational adjustment")
11	816	TOPIC: (access near/1 work)
12	17,472	TOPIC: (organi$ational culture)
13	201	TOPIC: (reasonable near/1 adjustment)
14	76	TOPIC: ("reasonable adjustment")
15	165	TOPIC: (jobseek*)
16	1,553	TOPIC: ("early retirement")
17	2,765	TOPIC: (health near/2 retirement)
18	278	TOPIC: ("disability discrimination")
19	29,693	TOPIC: (social security)
20	32	TOPIC: ("disability living allowance")
21	3	TOPIC: ("personal independence payment")
22	132,301	TOPIC: (corporat*)
23	4,354,148	TOPIC: ((trial) or (drug) or (imaging))
24	1,435,484	or/2-22
25	1,822	1 and 24
26	1,222	25 not 23

Cochrane Library

ID	Search	Hits
#1	MeSH descriptor: [Multiple Sclerosis] explode all trees	2324
#2	MeSH descriptor: [Employment] explode all trees	1664
#3	MeSH descriptor: [Rehabilitation, Vocational] explode all trees	419
#4	MeSH descriptor: [Work] explode all trees	482
#5	MeSH descriptor: [Occupations] explode all trees	166
#6	MeSH descriptor: [Organizational Culture] explode all trees	89
#7	MeSH descriptor: [Personnel Management] explode all trees	2145
#8	MeSH descriptor: [Social Security] explode all trees	42
#9	#2 or #3 or #4 or #5 or #6 or #7 or #8	3590
#10	#1 and #9	7
#11	multiple sclerosis:ti,ab,kw	6260
#12	employment	3683
#13	employ*	21520
#14	unemploy*	949
#15	self-employ*	77

#16	reemployment	18
#17	return* to work	1966
#18	worksite	644
#19	workplace	2100
#20	vocational rehabilitation	344
#21	absenteeism	1447
#22	reasonable adjustment*	4
#23	jobseek*	1
#24	early retirement	55
#25	(health) and (retirement)	291
#26	(disability) and (discrimination)	196
#27	disability living allowance	2
#28	corporat*	4979
#29	#1 or #11	6260
#30	#9 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28	31376
#31	#29 and #30	182

ProQuest

1	"multiple sclerosis"	129,077°
2	((employ?) OR (unemploy?) OR (self-employ?))	1,790,609°
3	reemployment	22,109°
4	(return? w/1 work)	82,521°
5	worksite OR workplace	1,067,987°
6	vocational w/1 rehabilitation	2,909°
7	absenteeism	127,582°
8	occupation?	532,130°
9	working w/1 conditions	168,200°
10	access w/1 work	118,666°
11	organi?ational w/1 culture	15,892°
12	reasonable w/1 adjustment	61,595°
13	jobseek?	19°
14	early w/1 retirment	66°
15	early w/1 retirement	18,662°
16	health w/2 retirement	12,882°
17	health w/2 retirement	12,882°
18	"disability discrimination"	9,562°
19	"social security"	645,880°

20	"disability living allowance"	1,189°
21	"personal independence payment"	158°
22	corporat?	29,180,974°
23	or/2-22	32,217,512
24	1 AND 23	36,857
25	(trial OR drug OR imaging)	9,609,847°
26	((("multiple sclerosis") AND (((employ?) OR (unemploy?) OR (self-employ?)) OR reemployment OR (return? w/1 work) OR (worksite OR workplace) OR (vocational w/1 rehabilitation) OR absenteeism OR occupation? OR (working w/1 conditions) OR (access w/1 work) OR (access w/2 work) OR (access w/1 work) OR (organi?ational w/1 culture) OR (reasonable w/1 adjustment?) OR (reasonable w/1 adjustment) OR jobseek? OR (early w/1 retirment) OR (early w/1 retirement) OR (health w/2 retirement) OR "disability discrimination" OR "social security" OR "disability living allowance" OR "personal independence payment" OR corporat?)) NOT (trial OR drug OR imaging))	7,049°

Appendix A.2 – CASP Scoring Sheet - Example

Vickers, M. H. (2009) Bullying, disability and work: a case study of workplace bullying.

Appraisal questions	**Comments**	0/1/2*
Screening: Was there a clear statement of the aims of the research?	Yes - to present a case study of someone with MS who was bullied out of her workplace	2
Screening: Is a qualitative methodology appropriate?	Yes definitely	2
Was the research design appropriate to address the aims of the research?	Yes	2
Was the recruitment strategy appropriate to the aims of the research?	*Yes – describes why this participant was used in this case study but not how came to be initially recruited*	1
Were the data collected in a way that addressed the research issue?	Data were used from a phenomenological interview study but presented here as narrative case study - Not clear if interviewed once or more	1
Has the relationship between researcher and participants been adequately considered?	Well described - author recognises her own bias and how this influences the data and makes it a part of her analysis	2
Have ethical issues been taken into consideration?	Pseudonym used and ethical approval	2
Was the data analysis sufficiently rigorous?	Not much detail given	1
	Score of 16:	13

Appendix A.3 – CASP Scoring Replication Process

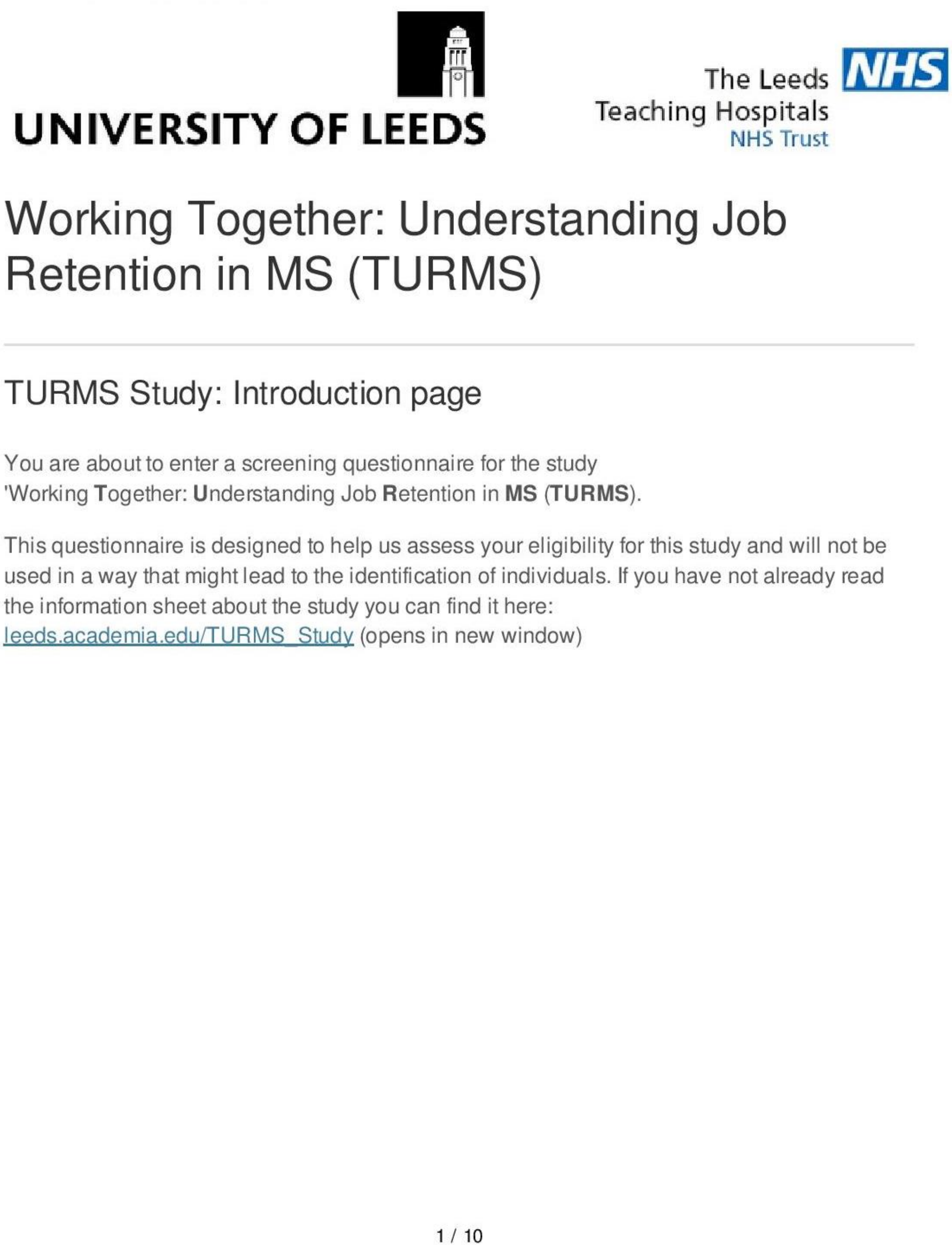
Article reference	Original CASP Score	Revised score	Supervisor's Score	Agreed Score
Gulick, E. E., Yam, M., & Touw, M. M. (1989) Work performance by persons with multiple sclerosis: Conditions that impede or enable the performance of work.	10		14	13
O'Day, B. (1998) Barriers for people with multiple sclerosis who want to work: A qualitative study.	9		11	9
Salomone, P. R., & O'Connell, K. R. (1998) The impact of disability on the career development of people with multiple sclerosis.	13		11	13
Jongbloed, L. (1998) Disability income: the experiences of women with multiple sclerosis.	13		11	11
Dyck, I., & Jongbloed, L. (2000) Women with multiple sclerosis and employment issues: A focus on social and institutional environments.	13	12		12
Yorkston, K. M., Johnson, K., Klasner, E. R., Amtmann, D., Kuehn, C. M., & Dudgeon, B. (2003) Getting the work done: A qualitative study of individuals with multiple sclerosis.	16	15		15
Johnson, K. L., Yorkston, K. M., Klasner, E. R., Kuehn, C. M., Johnson, E., & Amtmann, D. (2004) The cost and benefits of employment: a qualitative study of experiences of persons with multiple sclerosis.	16	15		15
O'Connor, R. J., Cano, S. J., Ramio i Torrenta, L., Thompson, A. J., & Playford, E. D. (2005) Factors influencing work retention for people with multiple sclerosis: cross-sectional studies using qualitative and quantitative methods.	13	14		14
Sweetland, J., Riazi, A., Cano, S. J., & Playford, E. D. (2007) Vocational rehabilitation services for people with multiple sclerosis: what patients want from clinicians and employers	14	13		13
Crooks, V. A., Dale Stone, S., & Owen, M. (2009) Multiple sclerosis and academic work: Socio-spatial strategies adopted to maintain employment.	12			12
Vickers, M. H. (2009) Bullying, disability and work: a case study of workplace bullying.	14	13	12	13
Cahill, M., Connolly, D., & Stapleton, T. (2010) Exploring occupational adaptation through the lives of women with multiple sclerosis.	16		13	14

Crooks, V. A., Stone, S. D., & Owen, M. (2011) Enabling university teaching for Canadian academics with multiple sclerosis through problem-focused coping.	15	14	14	14
Vickers, M. H. (2012) Antenarratives to inform health care research: exploring workplace illness disclosure for people with multiple sclerosis	15			15
McFadden, E., Horton, M. C., Ford, H. L., Gilworth, G., McFadden, M., & Tennant, A. (2012) Screening for the risk of job loss in multiple sclerosis	14			14
Vickers, M. H. (2012) "For the Crime of Being Different..."	9			9
Vickers (2012) Dark times for workers with disability: Shame experiences for workers with MS	10			10
Rumrill, P. D., Fraser, R. T., & Johnson, K. L. (2013) Employment and workplace accommodation outcomes among participants in a vocational consultation service for people with multiple sclerosis	12		14	14
Stone, S.-D., Crooks, V. A., & Owen, M. (2013) Going through the back door: Chronically ill academics' experiences as 'unexpected workers'.	14		15	14
Vickers, M. H. (2014) Disability and dirty workers: stories of physical, social and moral taint	12	9	11	10
Vickers (2014) Why People with MS are Really Leaving Work: From a Clayton's Choice to an Ugly Passage – A Phenomenological Study	12		10	11
Kirk-Brown, A. K., & Van Dijk, P. A. (2014) An empowerment model of workplace support following disclosure, for people with MS.	14			14
Jellie, B., Sweetland, J., Riazi, A., Cano, S. J., & Playford, E. D. (2014) Staying at work and living with MS: a qualitative study of the impact of a vocational rehabilitation intervention.	13			13
Coyne, K. S., Boscoe, A. N., Currie, B. M., Landrian, A. S., & Wandstrat, T. L. (2015) Understanding Drivers of Employment Changes in a Multiple Sclerosis Population	10	11	11	11
Vickers, M. H. (2015) Stories, Disability, and "Dirty" Workers: Creative Writing to Go Beyond Too Few Words	8		9	8
Vickers, M. H. (2015) Telling tales to share multiple truths: Disability and workplace bullying -- A semi-fiction case study	11		10	10

Bogenschutz, M., Rumrill Jr, P. D., Seward, H. E., Inge, K. J., & Hinterlong, P. C. (2016) Barriers to and Facilitators of Employment among Americans with Multiple Sclerosis: Results of a Qualitative Focus Group Study	15		14	15
Meade, M., Reed, K. S., Rumrill, P., Aust, R., & Krause, J. S. (2016) Perceptions of Quality of Employment Outcomes after Multiple Sclerosis: A Qualitative Study	15			15
Van Capelle A, Visser LH, Vosman F (2016) Multiple Sclerosis and Work: An Interpretative Phenomenological Analysis of the Perspective of Persons with Early Stage MS	15			15
Vickers (2017) Dark Secrets and Impression Management: Workplace Masks of People with Multiple Sclerosis (MS)	14		14	14
Hanneke van der Meide, Dennis van Gorp, Karin van der Hiele & Leo Visser (2017) Always looking for a new balance": toward an understanding of what it takes to continue working while being diagnosed with relapsing-remitting multiple sclerosis	16		12	12

Appendix B – Participant Questionnaires

Appendix B.1 – Eligibility Questionnaire



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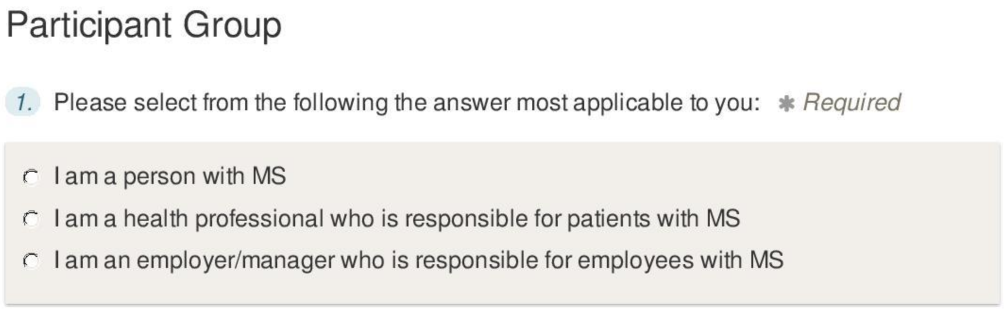
Teaching Hospitals
NHS Trust

Working Together: Understanding Job Retention in MS (TURMS)

TURMS Study: Introduction page

You are about to enter a screening questionnaire for the study 'Working **T**ogether: **U**nderstanding Job **R**etention in **MS** (**TURMS**).

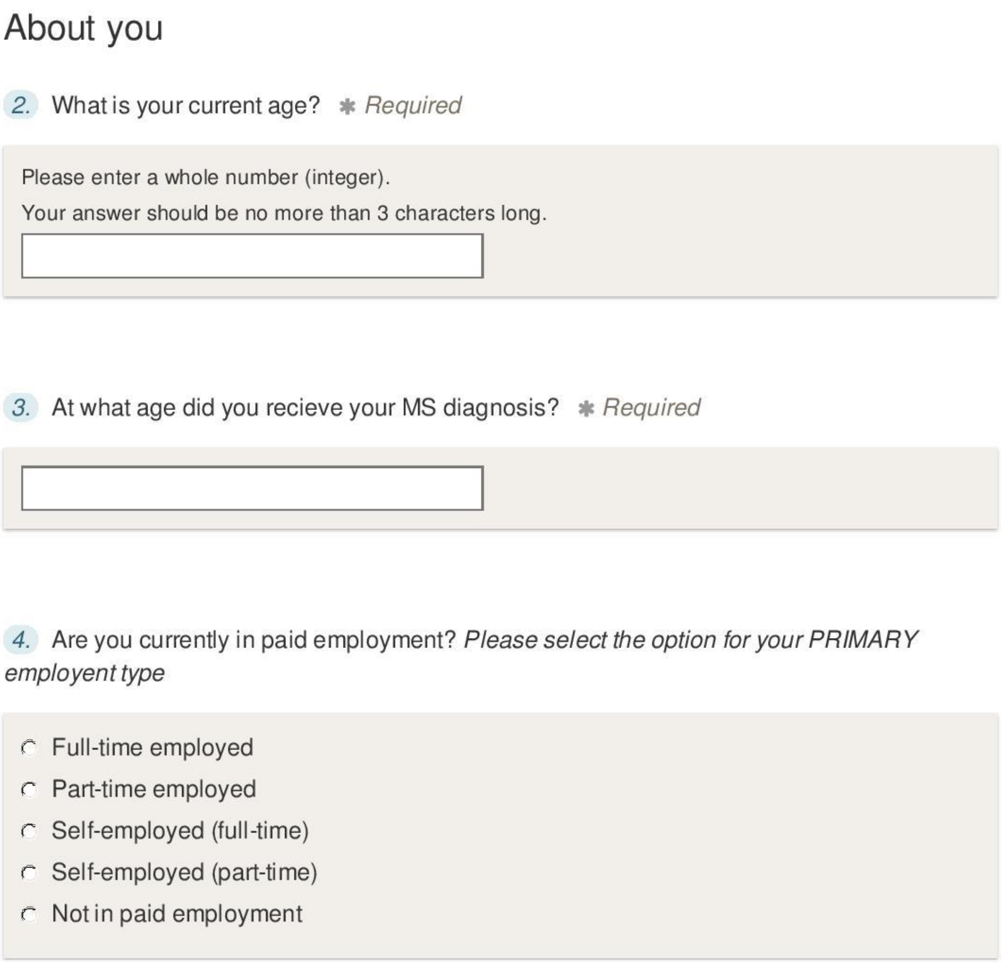
This questionnaire is designed to help us assess your eligibility for this study and will not be used in a way that might lead to the identification of individuals. If you have not already read the information sheet about the study you can find it here: leeds.academia.edu/TURMS_Study (opens in new window)



Participant Group

1. Please select from the following the answer most applicable to you: ✱ *Required*

○ I am a person with MS
○ I am a health professional who is responsible for patients with MS
○ I am an employer/manager who is responsible for employees with MS



About you

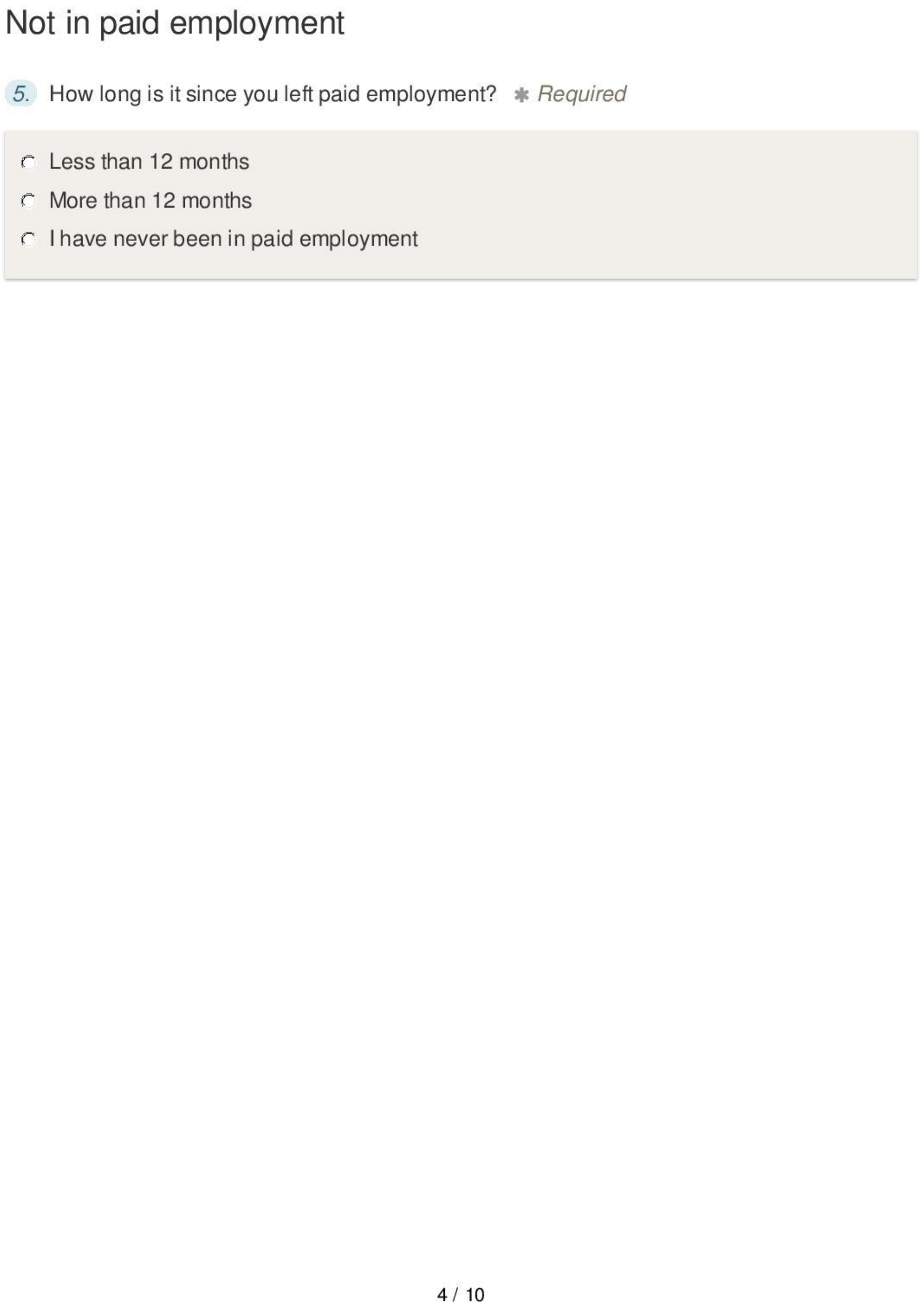
2. What is your current age? ✱ *Required*

Please enter a whole number (integer).
Your answer should be no more than 3 characters long.

3. At what age did you recieve your MS diagnosis? ✱ *Required*

4. Are you currently in paid employment? *Please select the option for your PRIMARY employent type*

- ○ Full-time employed
- ○ Part-time employed
- ○ Self-employed (full-time)
- ○ Self-employed (part-time)
- ○ Not in paid employment



Not in paid employment

5. How long is it since you left paid employment? ✱ *Required*

○ Less than 12 months
○ More than 12 months
○ I have never been in paid employment

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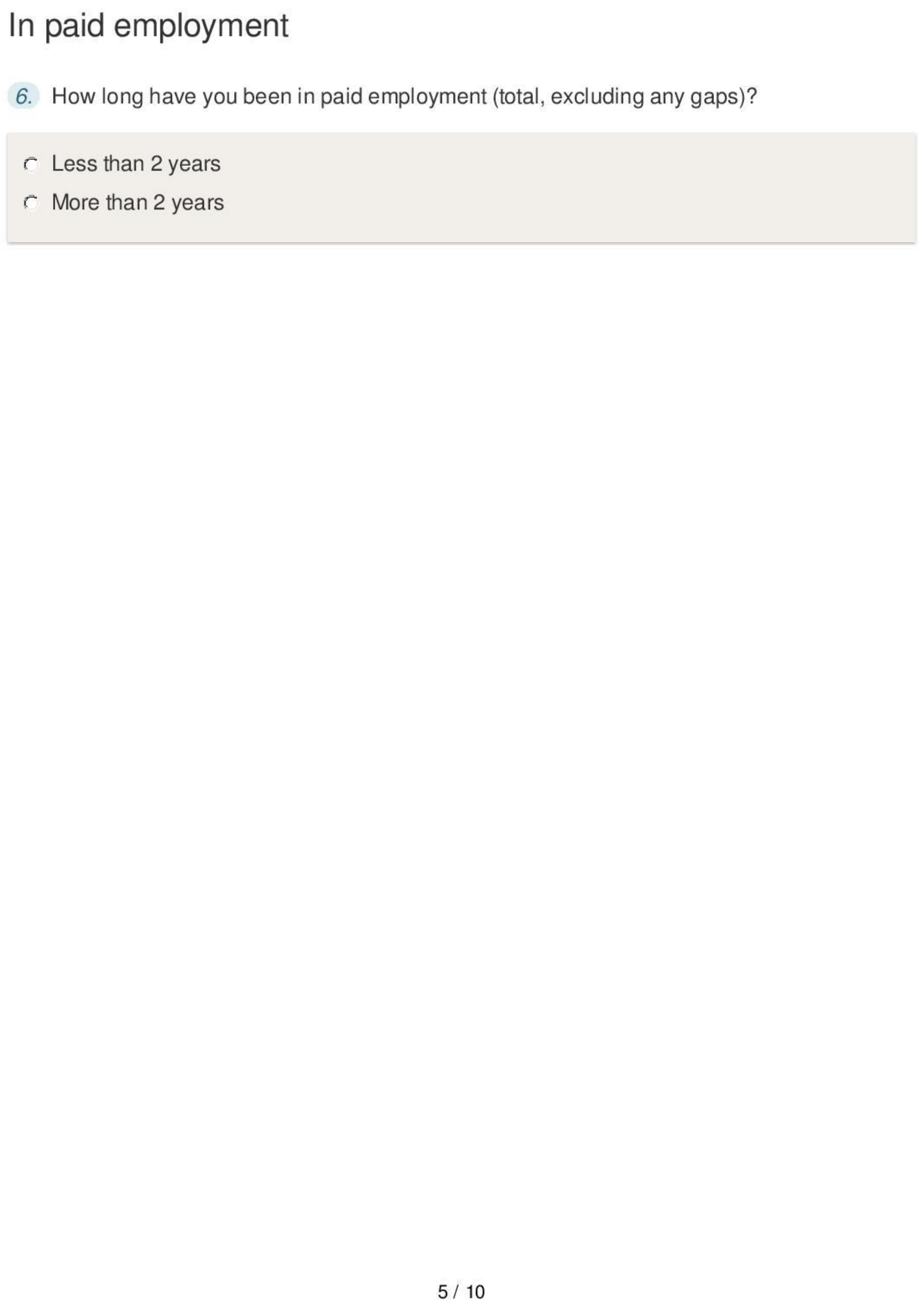
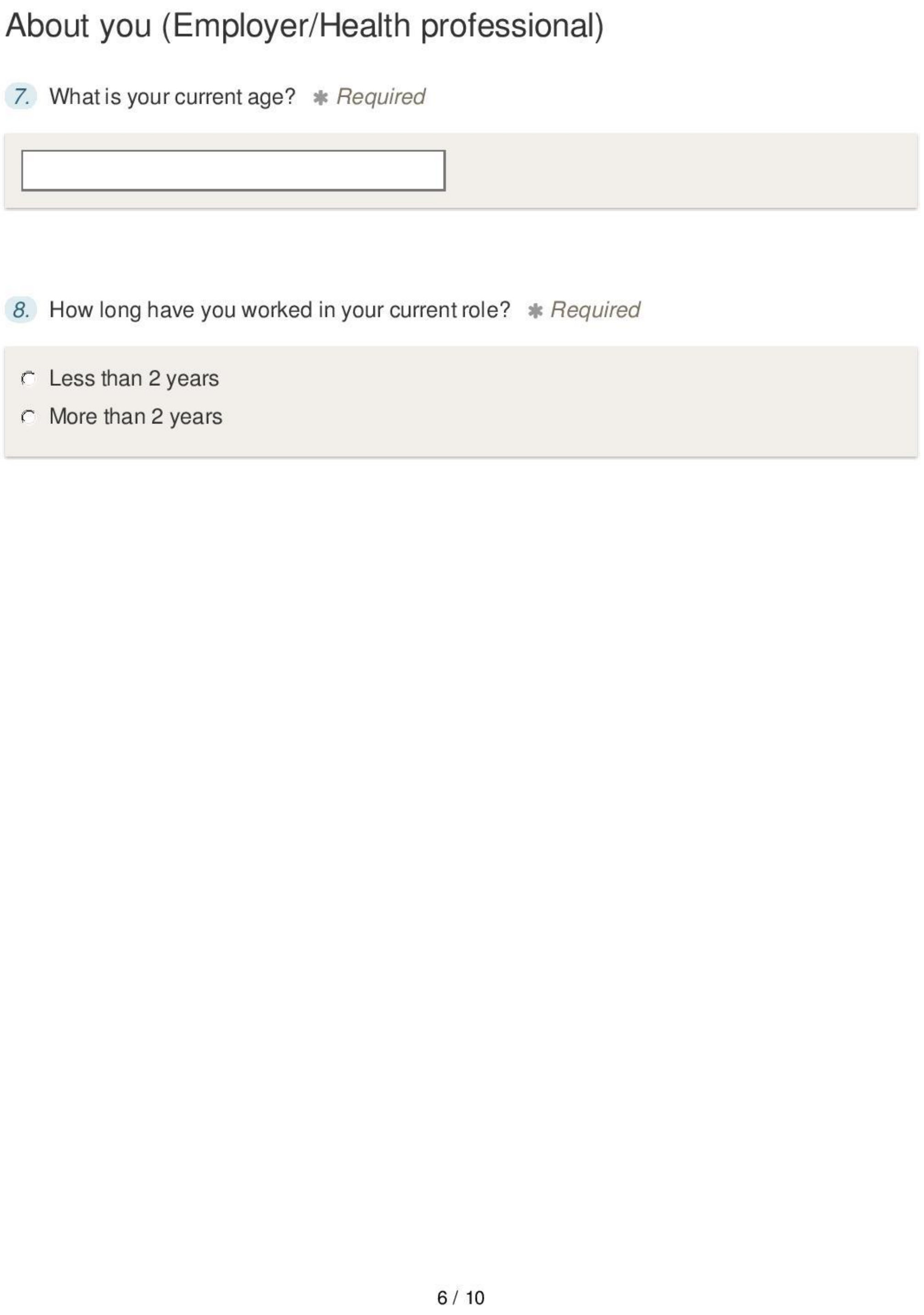


In paid employment

6. How long have you been in paid employment (total, excluding any gaps)?

○ Less than 2 years
○ More than 2 years

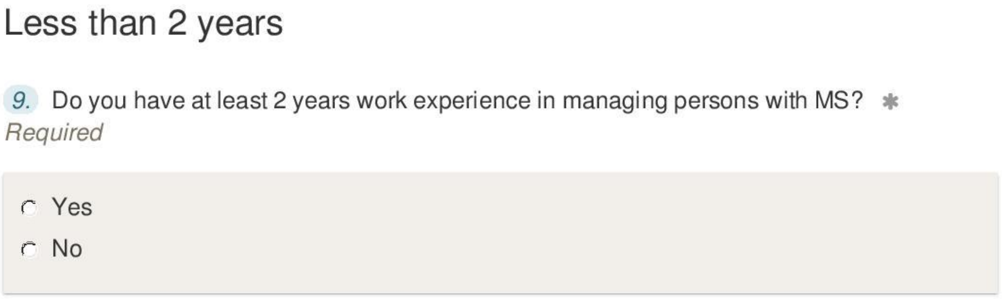


About you (Employer/Health professional)

7. What is your current age? ✱ *Required*

8. How long have you worked in your current role? ✱ *Required*

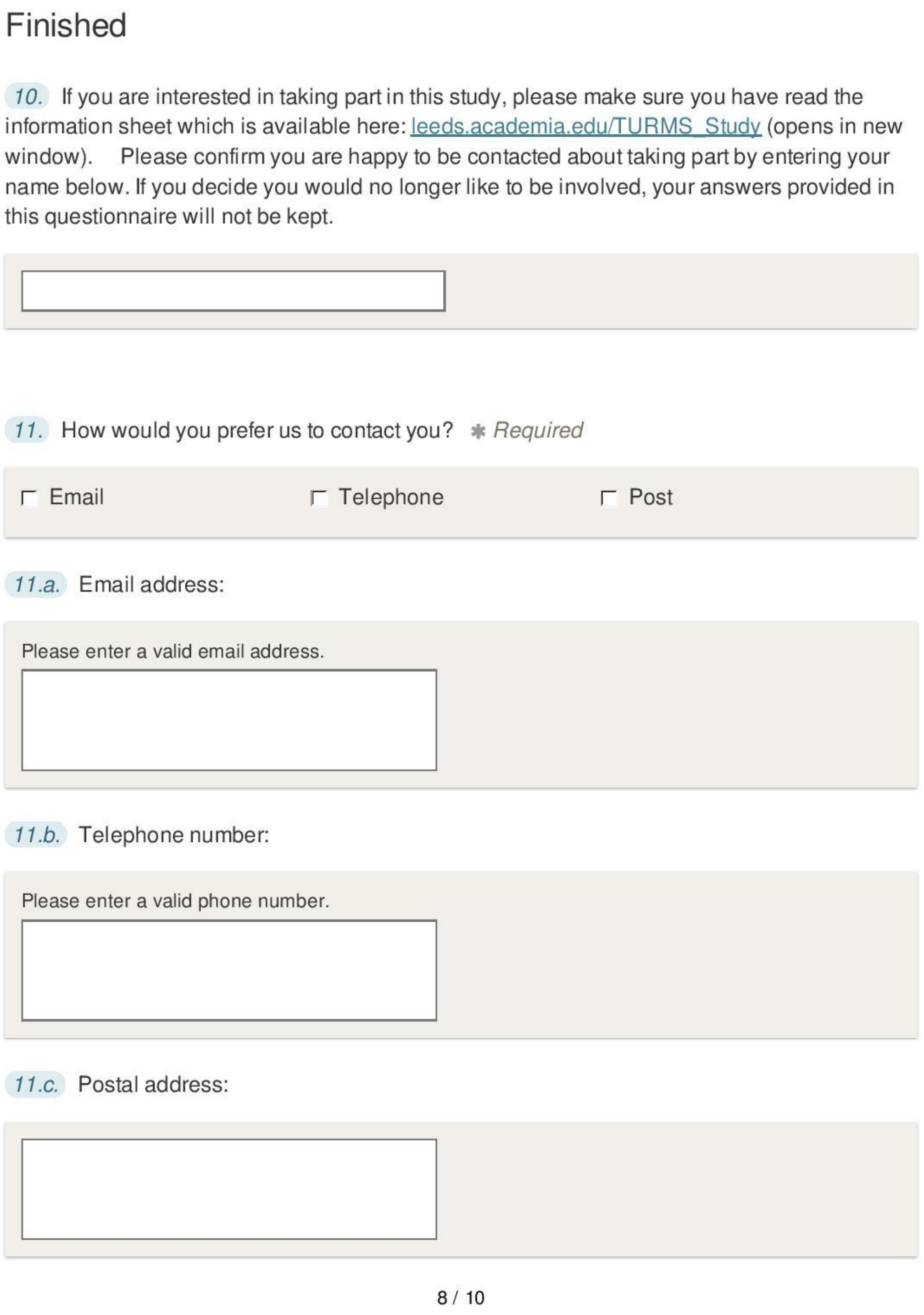
○ Less than 2 years
○ More than 2 years



Less than 2 years

9. Do you have at least 2 years work experience in managing persons with MS? *
Required

○ Yes
○ No



Finished

10. If you are interested in taking part in this study, please make sure you have read the information sheet which is available here: leeds.academia.edu/TURMS_Study (opens in new window). Please confirm you are happy to be contacted about taking part by entering your name below. If you decide you would no longer like to be involved, your answers provided in this questionnaire will not be kept.

11. How would you prefer us to contact you? ✱ *Required*

☐ Email ☐ Telephone ☐ Post

11.a. Email address:

Please enter a valid email address.

11.b. Telephone number:

Please enter a valid phone number.

11.c. Postal address:

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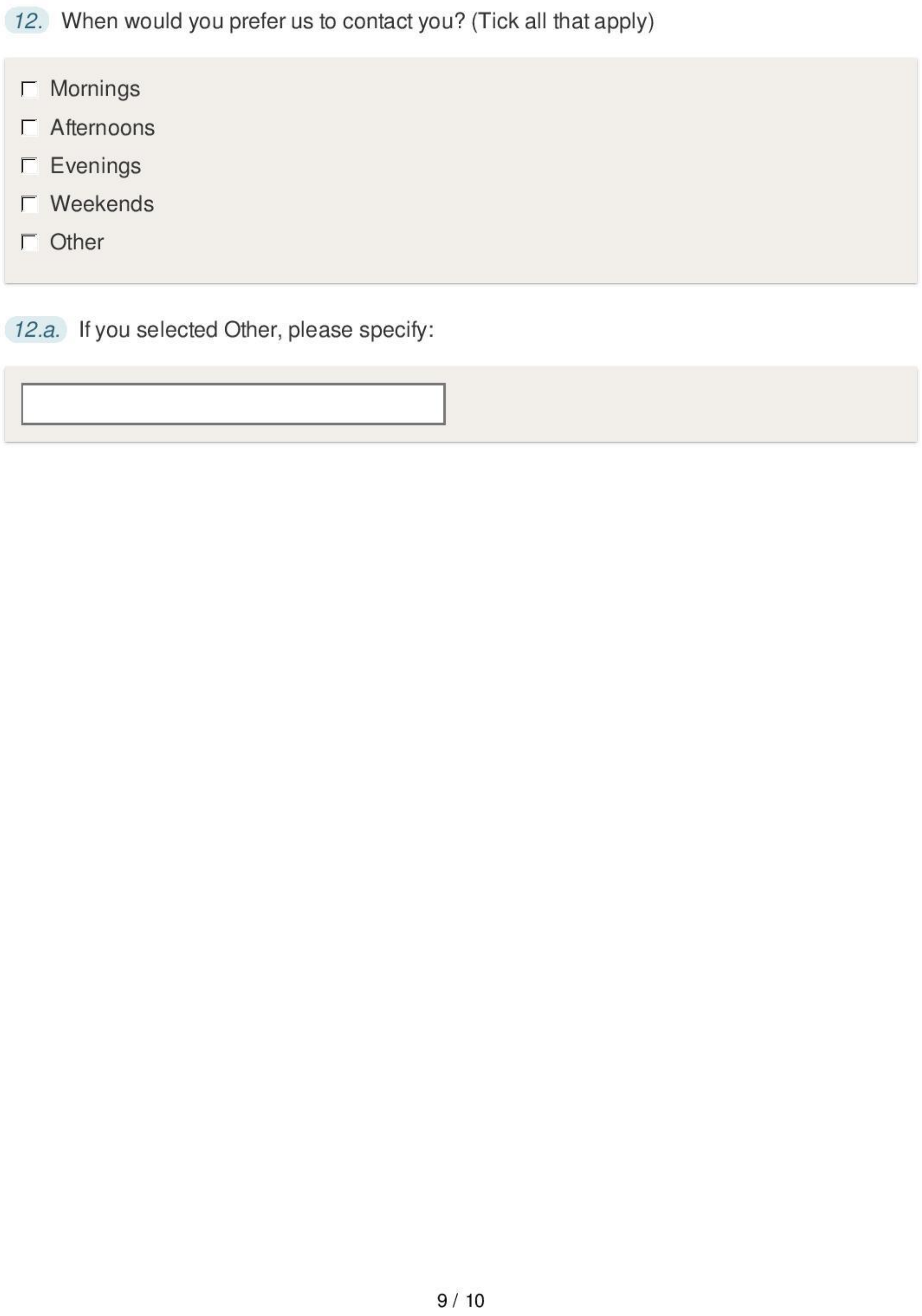
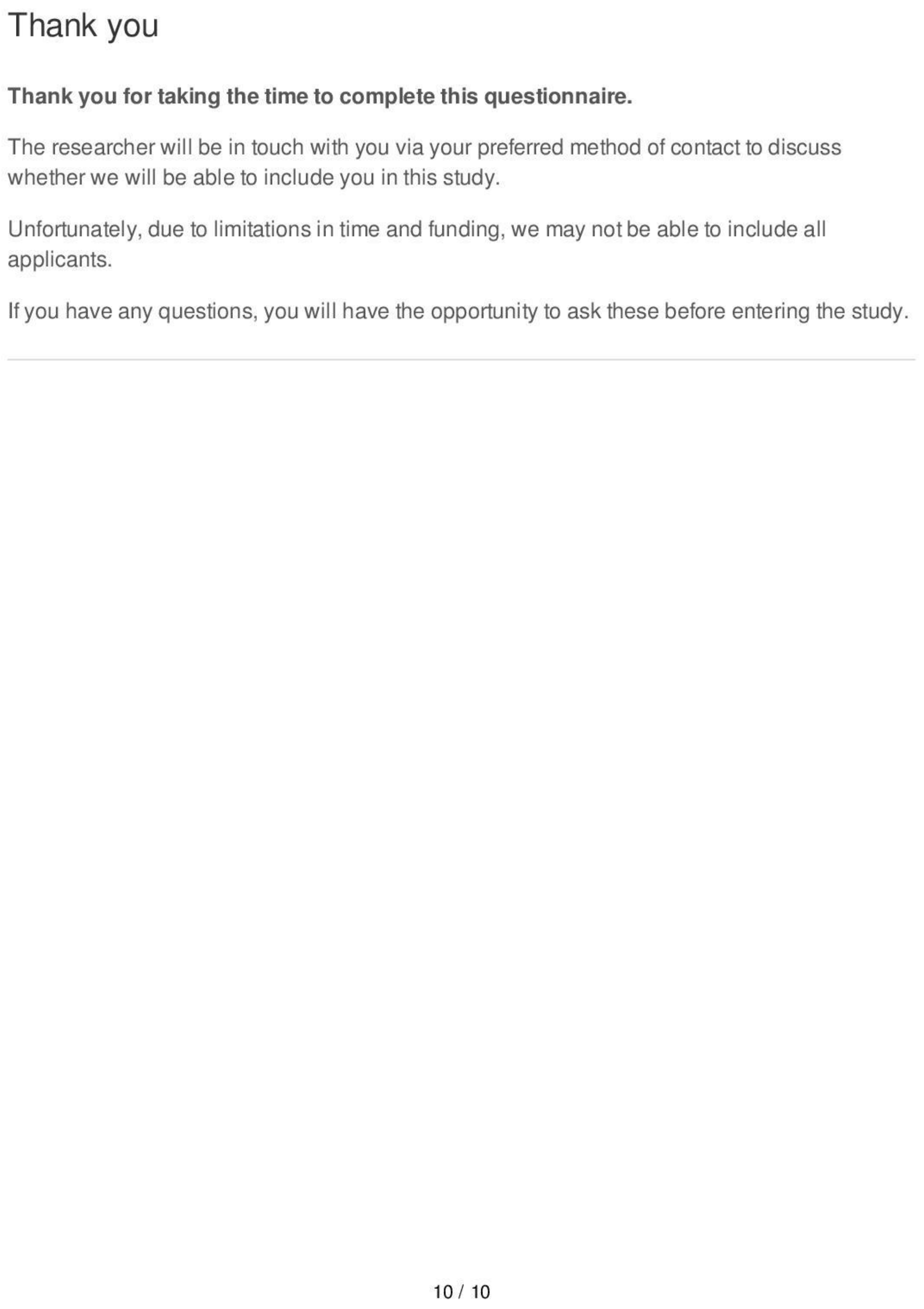


12. When would you prefer us to contact you? (Tick all that apply)

- ☐ Mornings
- ☐ Afternoons
- ☐ Evenings
- ☐ Weekends
- ☐ Other

12.a. If you selected Other, please specify:



Thank you

Thank you for taking the time to complete this questionnaire.

The researcher will be in touch with you via your preferred method of contact to discuss whether we will be able to include you in this study.

Unfortunately, due to limitations in time and funding, we may not be able to include all applicants.

If you have any questions, you will have the opportunity to ask these before entering the study.

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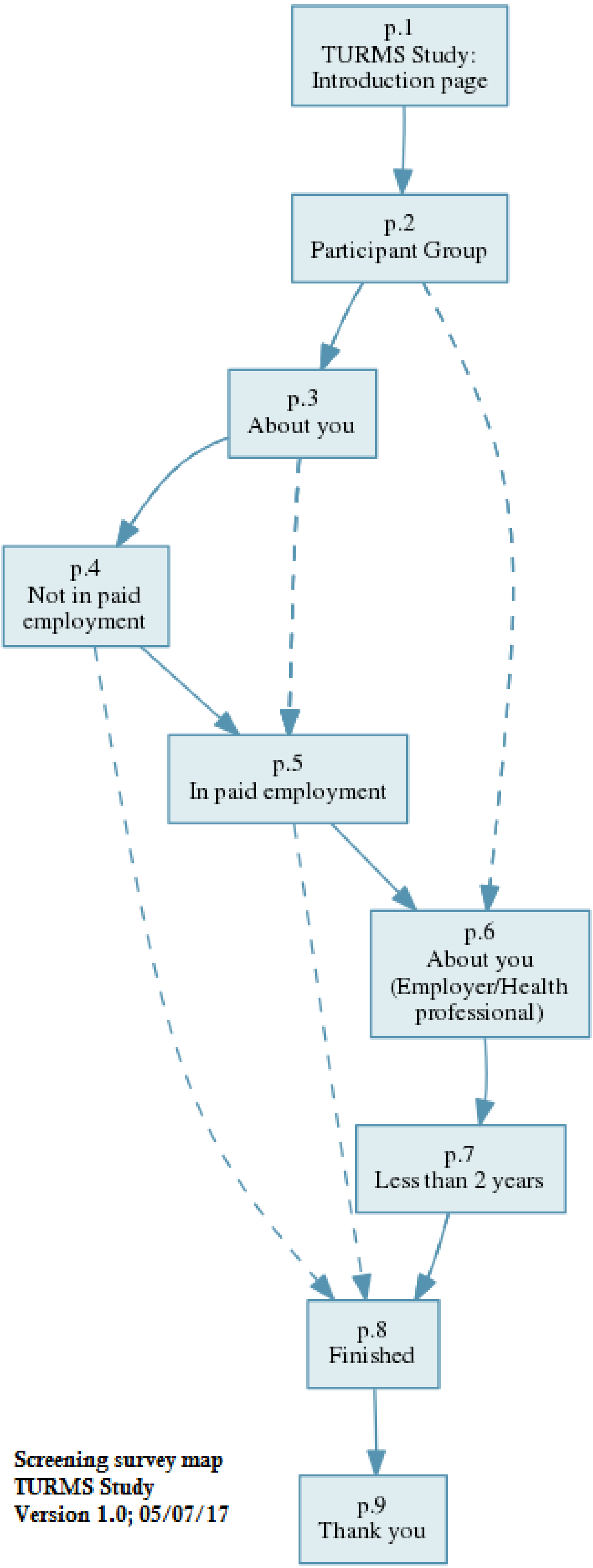
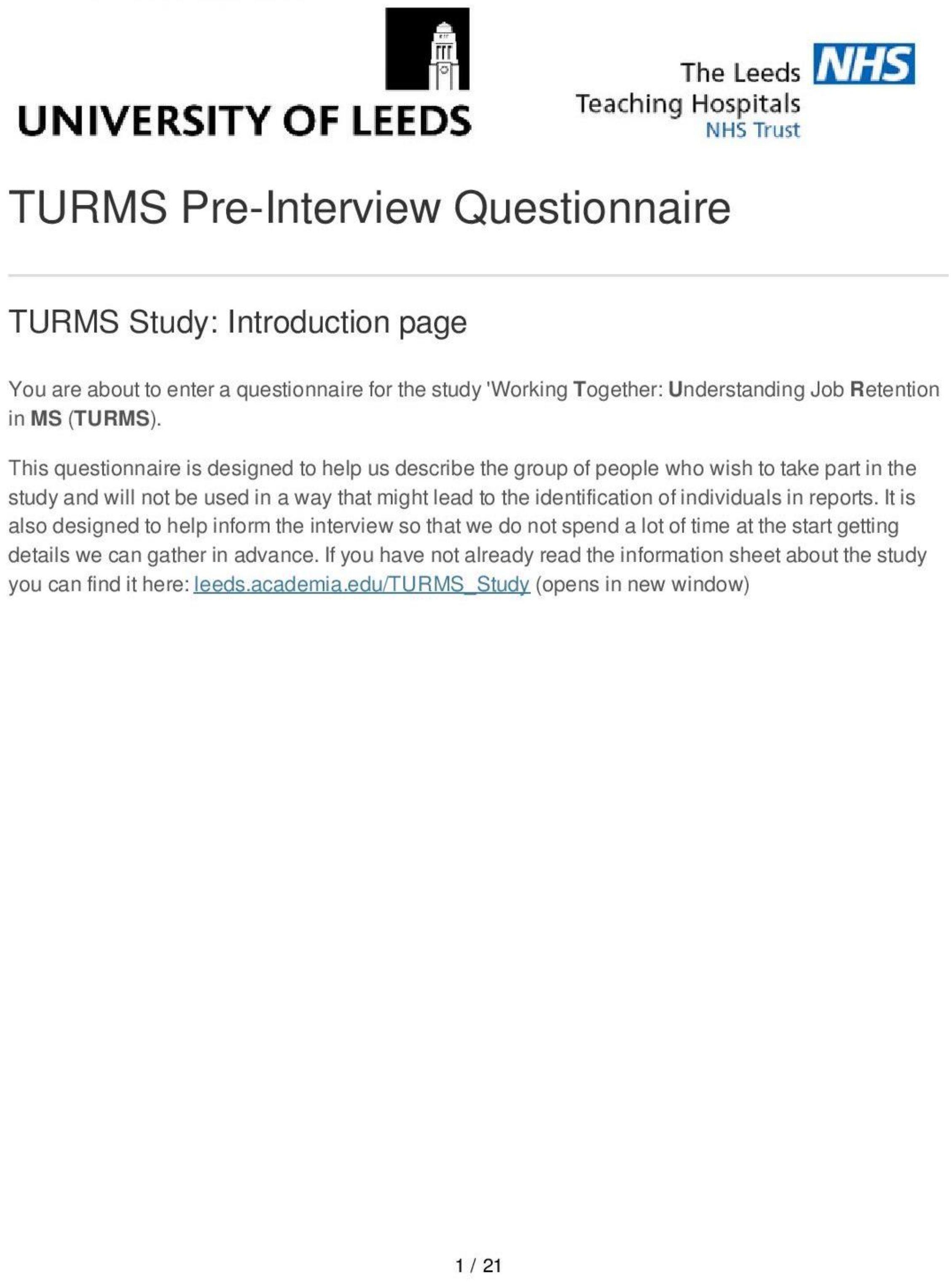
Appendix B.2 – Eligibility Questionnaire Route Map



Screening survey map
TURMS Study
Version 1.0; 05/07/17

Appendix B.3 – Pre-Interview Survey



UNIVERSITY OF LEEDS

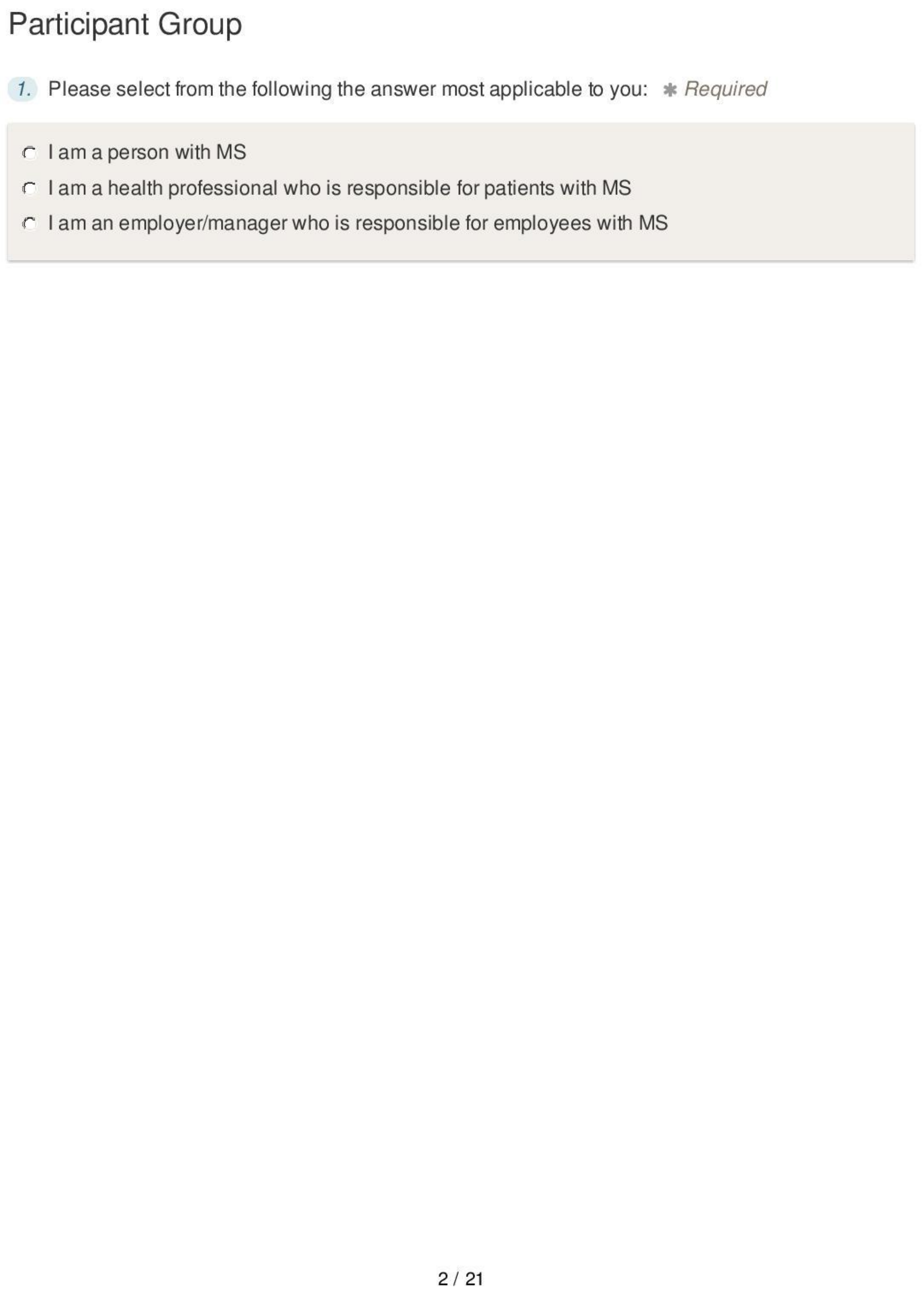
The Leeds Teaching Hospitals NHS Trust

TURMS Pre-Interview Questionnaire

TURMS Study: Introduction page

You are about to enter a questionnaire for the study 'Working **T**ogether: **U**nderstanding Job **R**etention in **MS** (**TURMS**).

This questionnaire is designed to help us describe the group of people who wish to take part in the study and will not be used in a way that might lead to the identification of individuals in reports. It is also designed to help inform the interview so that we do not spend a lot of time at the start getting details we can gather in advance. If you have not already read the information sheet about the study you can find it here: leeds.academia.edu/TURMS_Study (opens in new window)



Participant Group

1. Please select from the following the answer most applicable to you: ✱ *Required*

○ I am a person with MS
○ I am a health professional who is responsible for patients with MS
○ I am an employer/manager who is responsible for employees with MS

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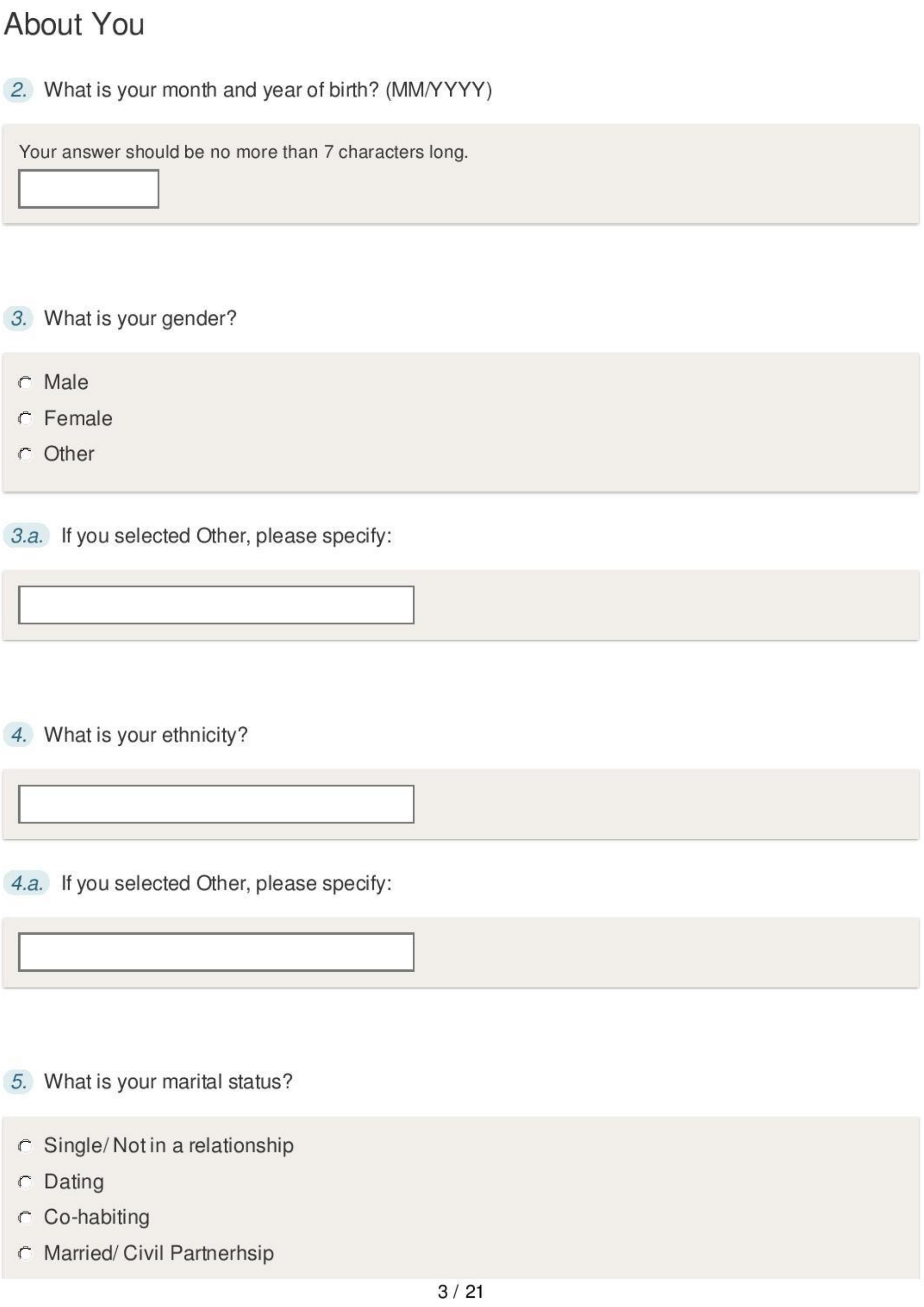

About You

2. What is your month and year of birth? (MM/YYYY)

Your answer should be no more than 7 characters long.

3. What is your gender?

○ Male
○ Female
○ Other

3.a. If you selected Other, please specify:

4. What is your ethnicity?

4.a. If you selected Other, please specify:

5. What is your marital status?

○ Single/ Not in a relationship
○ Dating
○ Co-habiting
○ Married/ Civil Partnerhsip

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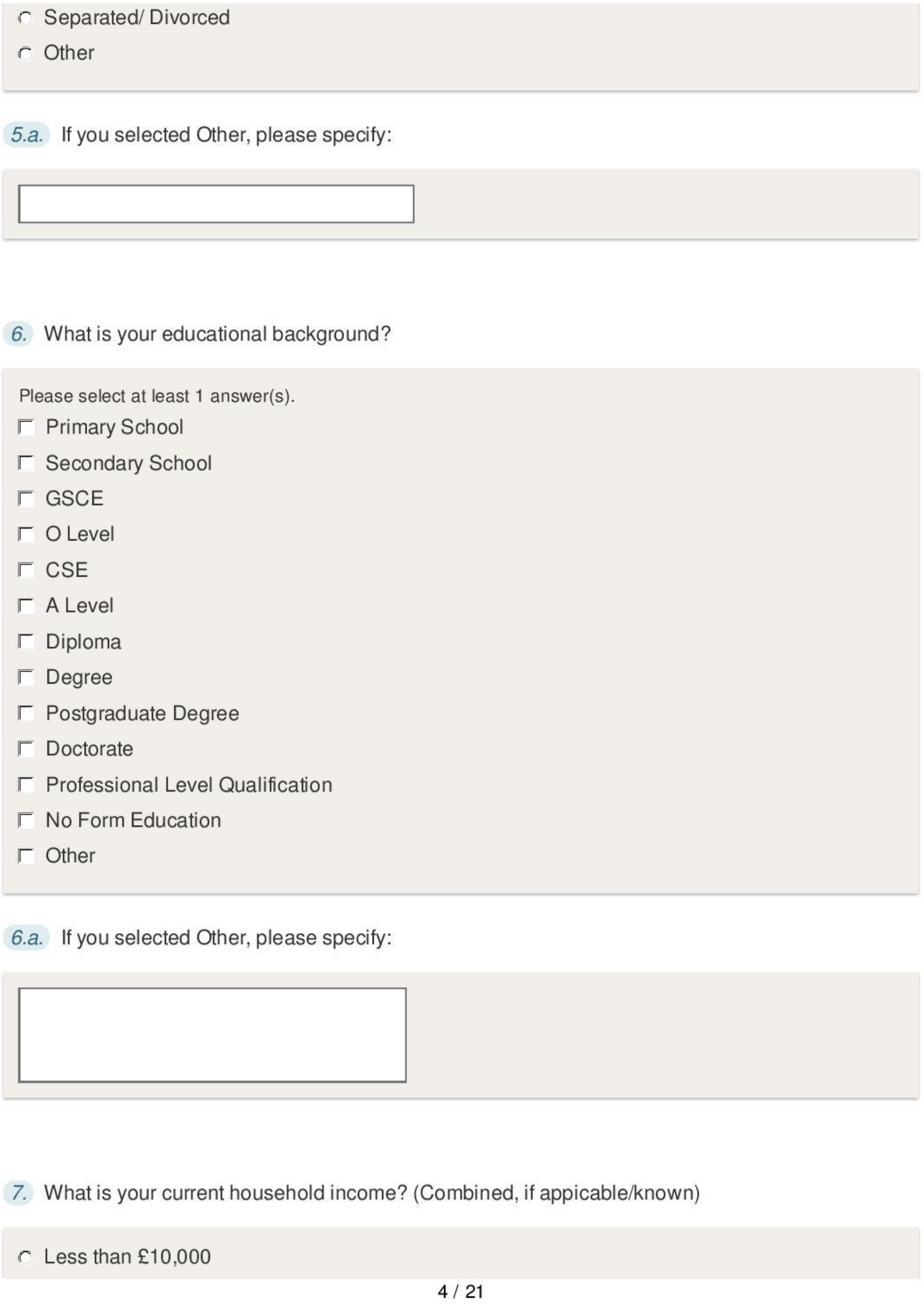


○ Separated/ Divorced
○ Other

5.a. If you selected Other, please specify:

6. What is your educational background?

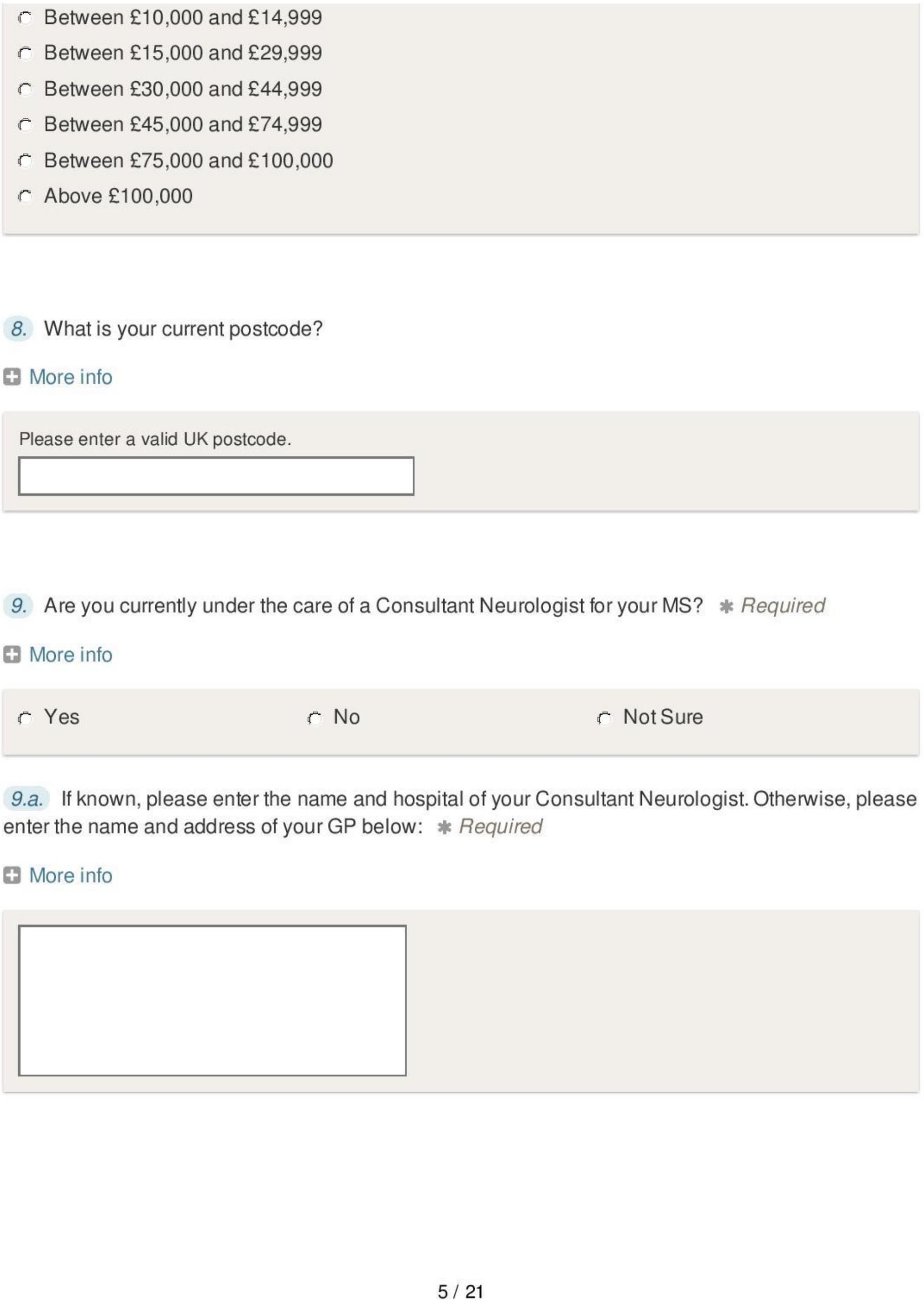
Please select at least 1 answer(s).

☐ Primary School
☐ Secondary School
☐ GSCE
☐ O Level
☐ CSE
☐ A Level
☐ Diploma
☐ Degree
☐ Postgraduate Degree
☐ Doctorate
☐ Professional Level Qualification
☐ No Form Education
☐ Other

6.a. If you selected Other, please specify:

7. What is your current household income? (Combined, if appicable/known)

○ Less than £10,000



○ Between £10,000 and £14,999
○ Between £15,000 and £29,999
○ Between £30,000 and £44,999
○ Between £45,000 and £74,999
○ Between £75,000 and £100,000
○ Above £100,000

8. What is your current postcode?

⊞ More info

Please enter a valid UK postcode.

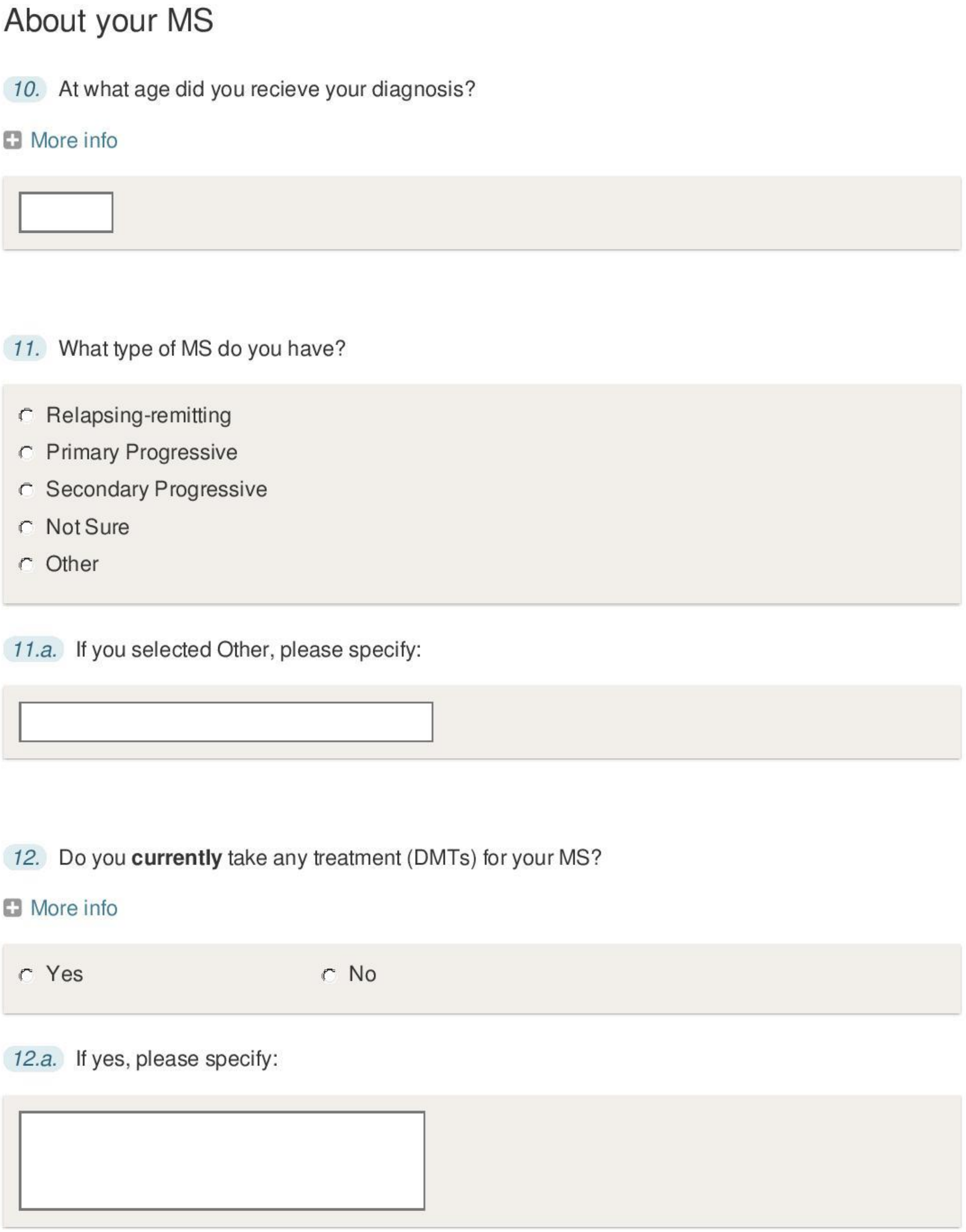
9. Are you currently under the care of a Consultant Neurologist for your MS? ✱ *Required*

⊞ More info

○ Yes ○ No ○ Not Sure

9.a. If known, please enter the name and hospital of your Consultant Neurologist. Otherwise, please enter the name and address of your GP below: ✱ *Required*

⊞ More info



About your MS

10. At what age did you recieve your diagnosis?

⊞ More info

☐

11. What type of MS do you have?

○ Relapsing-remitting
○ Primary Progressive
○ Secondary Progressive
○ Not Sure
○ Other

11.a. If you selected Other, please specify:

☐

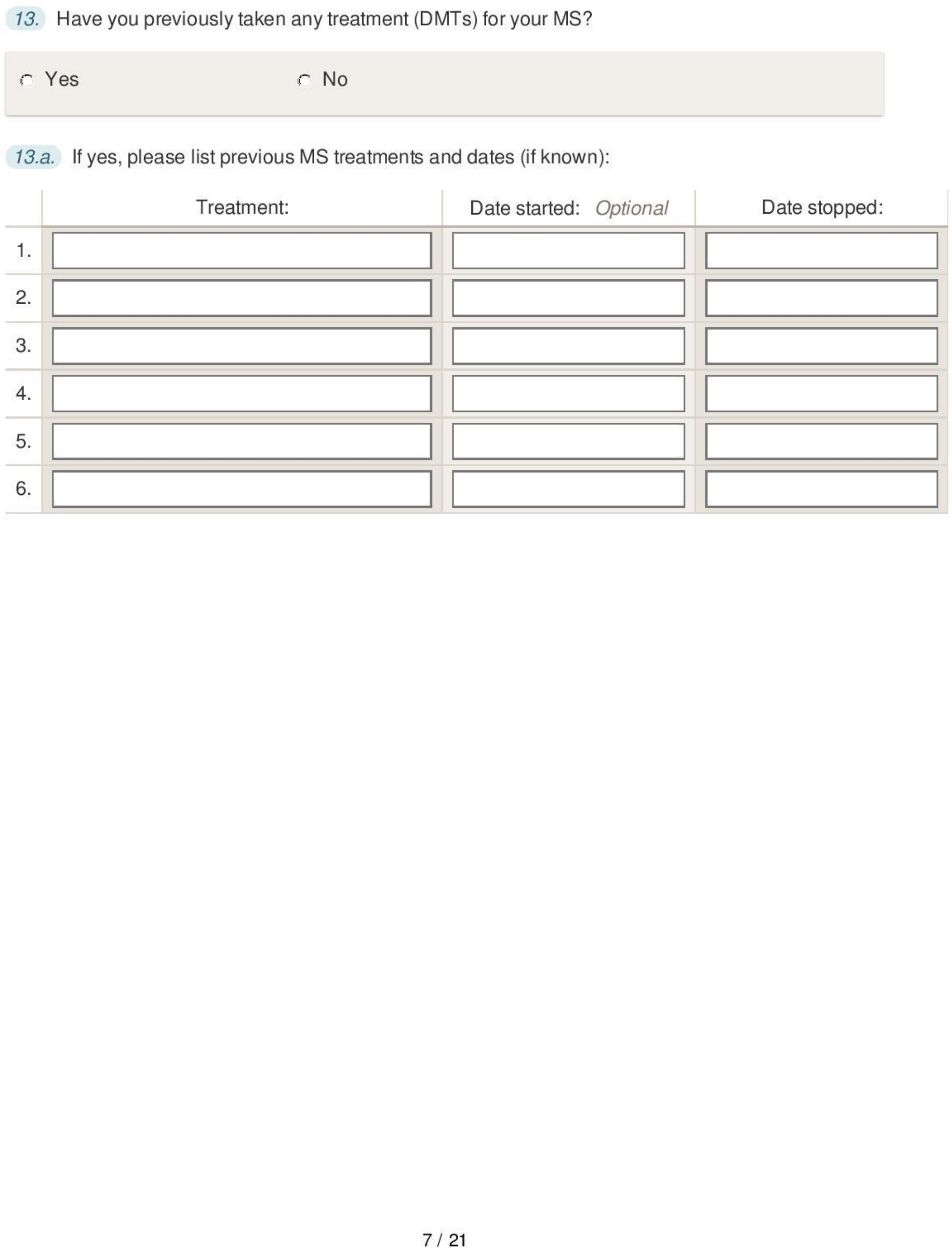
12. Do you **currently** take any treatment (DMTs) for your MS?

⊞ More info

○ Yes ○ No

12.a. If yes, please specify:

☐



13. Have you previously taken any treatment (DMTs) for your MS?

○ Yes ○ No

13.a. If yes, please list previous MS treatments and dates (if known):

	Treatment:	Date started: *Optional*	Date stopped:
1.			
2.			
3.			
4.			
5.			
6.			

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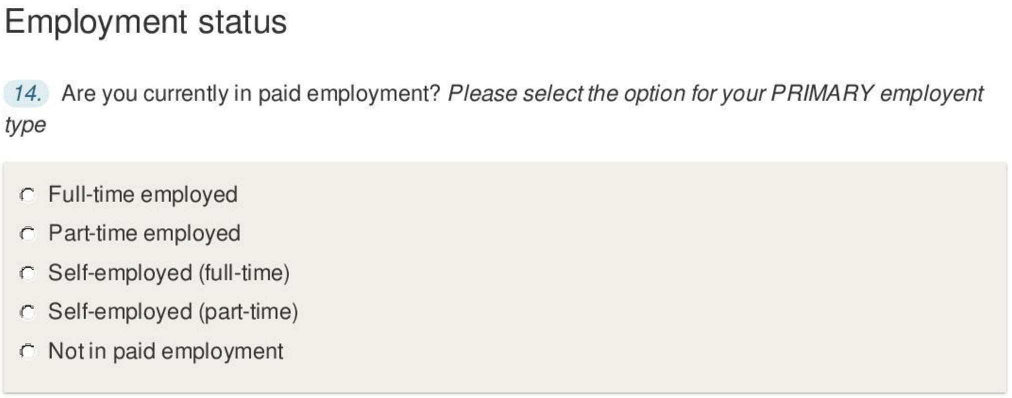
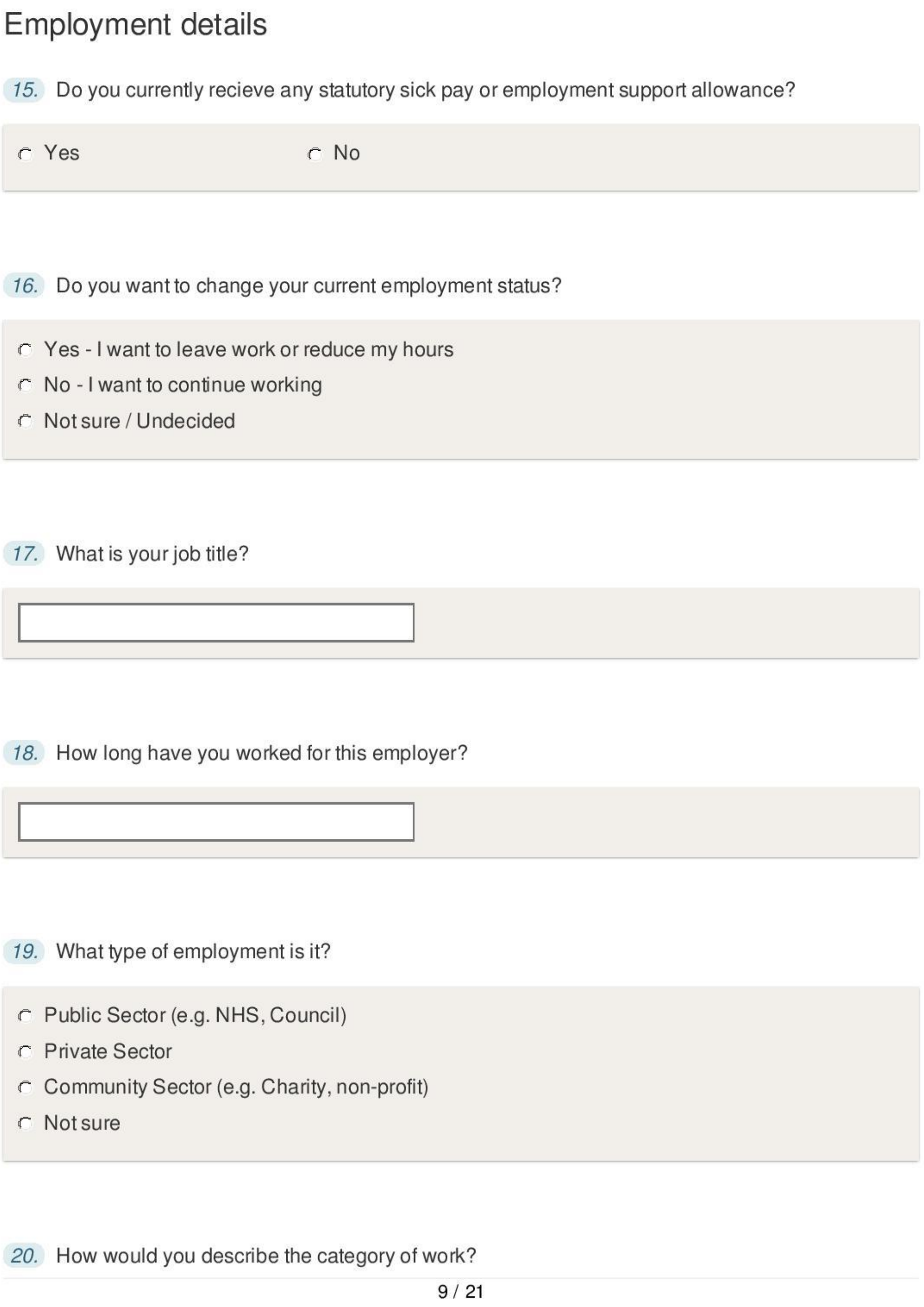


Employment status

14. Are you currently in paid employment? *Please select the option for your PRIMARY employent type*

- ○ Full-time employed
- ○ Part-time employed
- ○ Self-employed (full-time)
- ○ Self-employed (part-time)
- ○ Not in paid employment



Employment details

15. Do you currently recieve any statutory sick pay or employment support allowance?

○ Yes ○ No

16. Do you want to change your current employment status?

○ Yes - I want to leave work or reduce my hours
○ No - I want to continue working
○ Not sure / Undecided

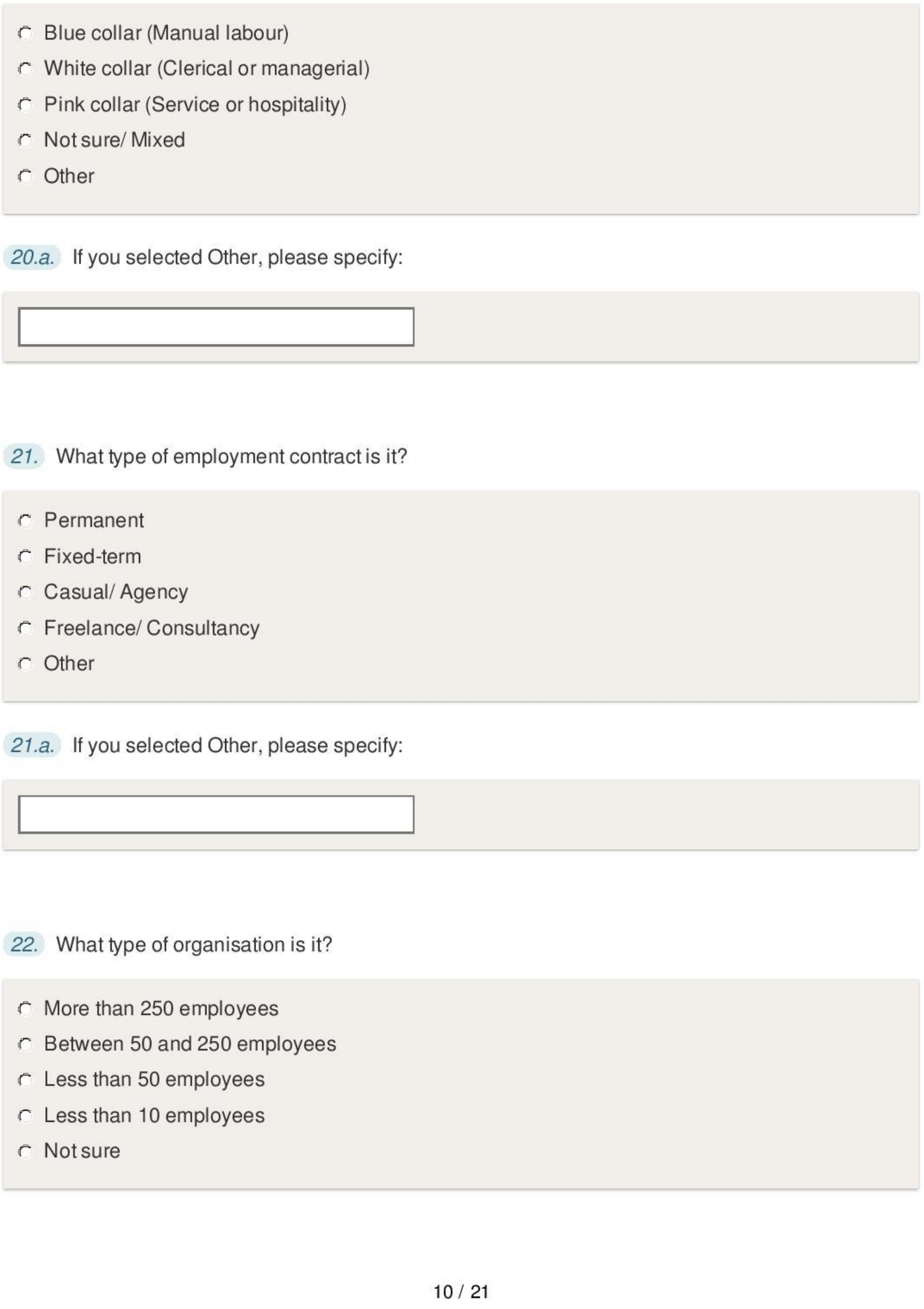
17. What is your job title?

18. How long have you worked for this employer?

19. What type of employment is it?

○ Public Sector (e.g. NHS, Council)
○ Private Sector
○ Community Sector (e.g. Charity, non-profit)
○ Not sure

20. How would you describe the category of work?



- ○ Blue collar (Manual labour)
- ○ White collar (Clerical or managerial)
- ○ Pink collar (Service or hospitality)
- ○ Not sure/ Mixed
- ○ Other

20.a. If you selected Other, please specify:

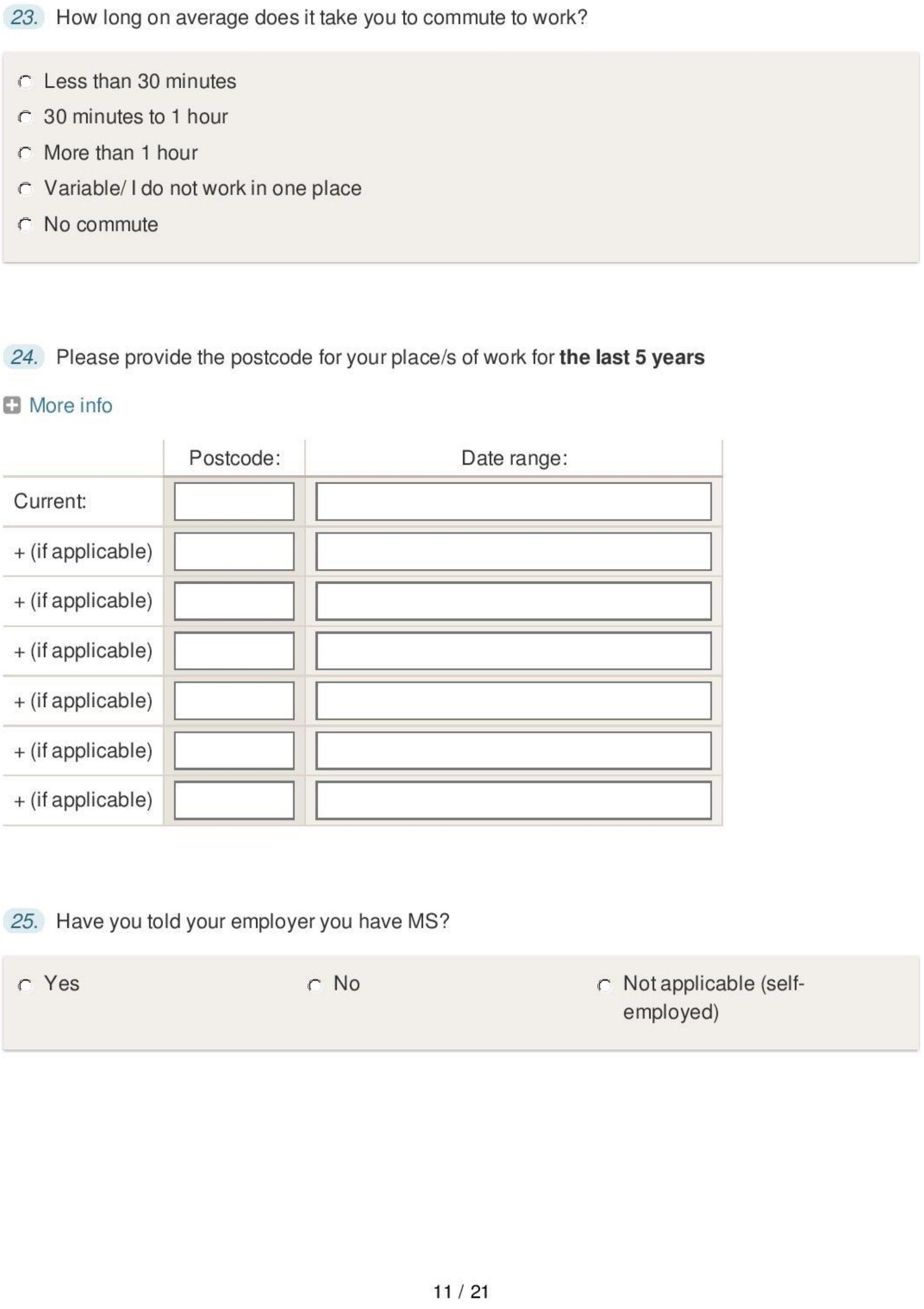
21. What type of employment contract is it?

- ○ Permanent
- ○ Fixed-term
- ○ Casual/ Agency
- ○ Freelance/ Consultancy
- ○ Other

21.a. If you selected Other, please specify:

22. What type of organisation is it?

- ○ More than 250 employees
- ○ Between 50 and 250 employees
- ○ Less than 50 employees
- ○ Less than 10 employees
- ○ Not sure



23. How long on average does it take you to commute to work?

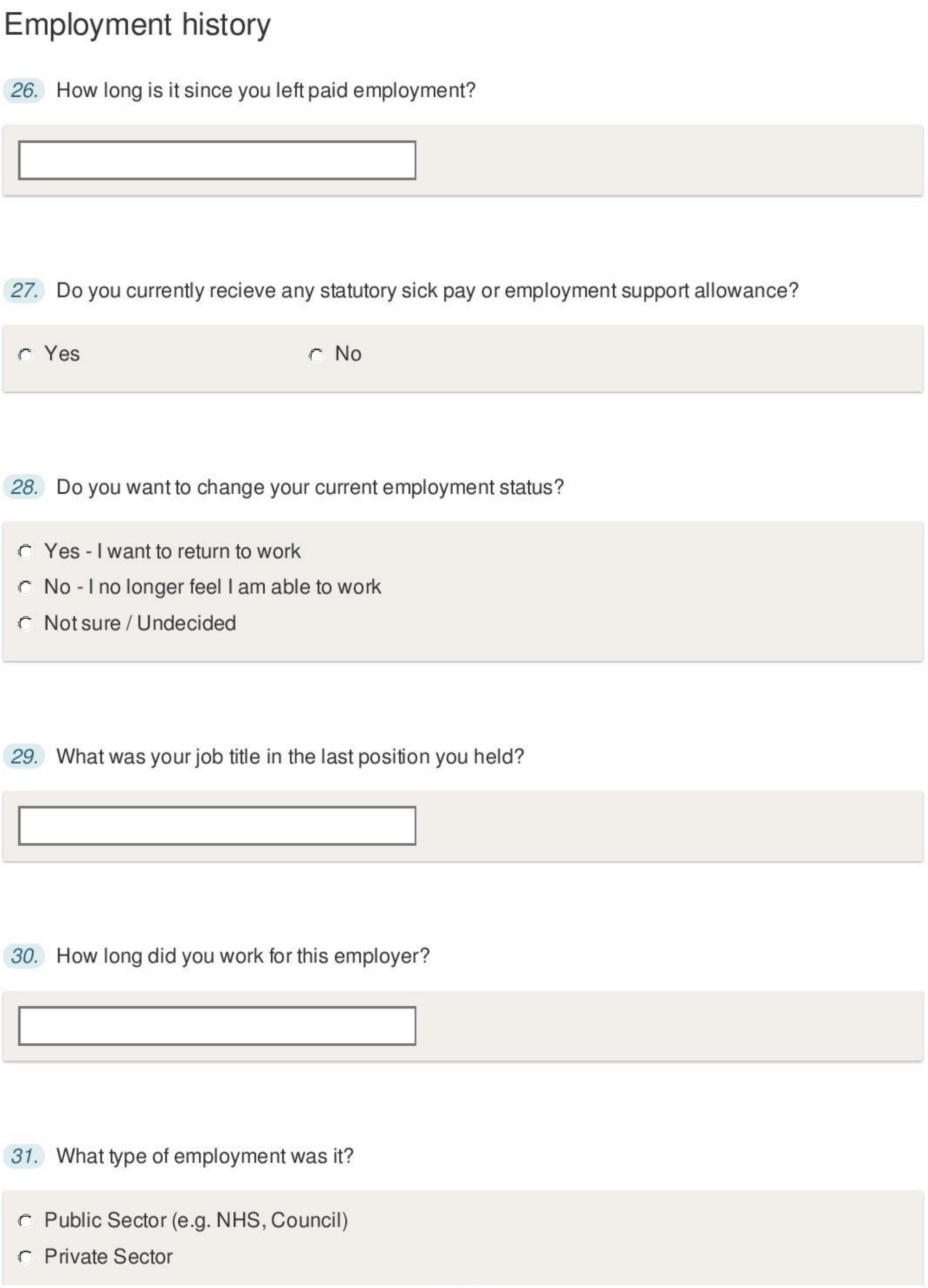
○ Less than 30 minutes
○ 30 minutes to 1 hour
○ More than 1 hour
○ Variable/ I do not work in one place
○ No commute

24. Please provide the postcode for your place/s of work for **the last 5 years**

	Postcode:	Date range:
Current:		
+ (if applicable)		
+ (if applicable)		
+ (if applicable)		
+ (if applicable)		
+ (if applicable)		
+ (if applicable)		

25. Have you told your employer you have MS?

○ Yes ○ No ○ Not applicable (self-employed)



Employment history

26. How long is it since you left paid employment?

27. Do you currently recieve any statutory sick pay or employment support allowance?

○ Yes ○ No

28. Do you want to change your current employment status?

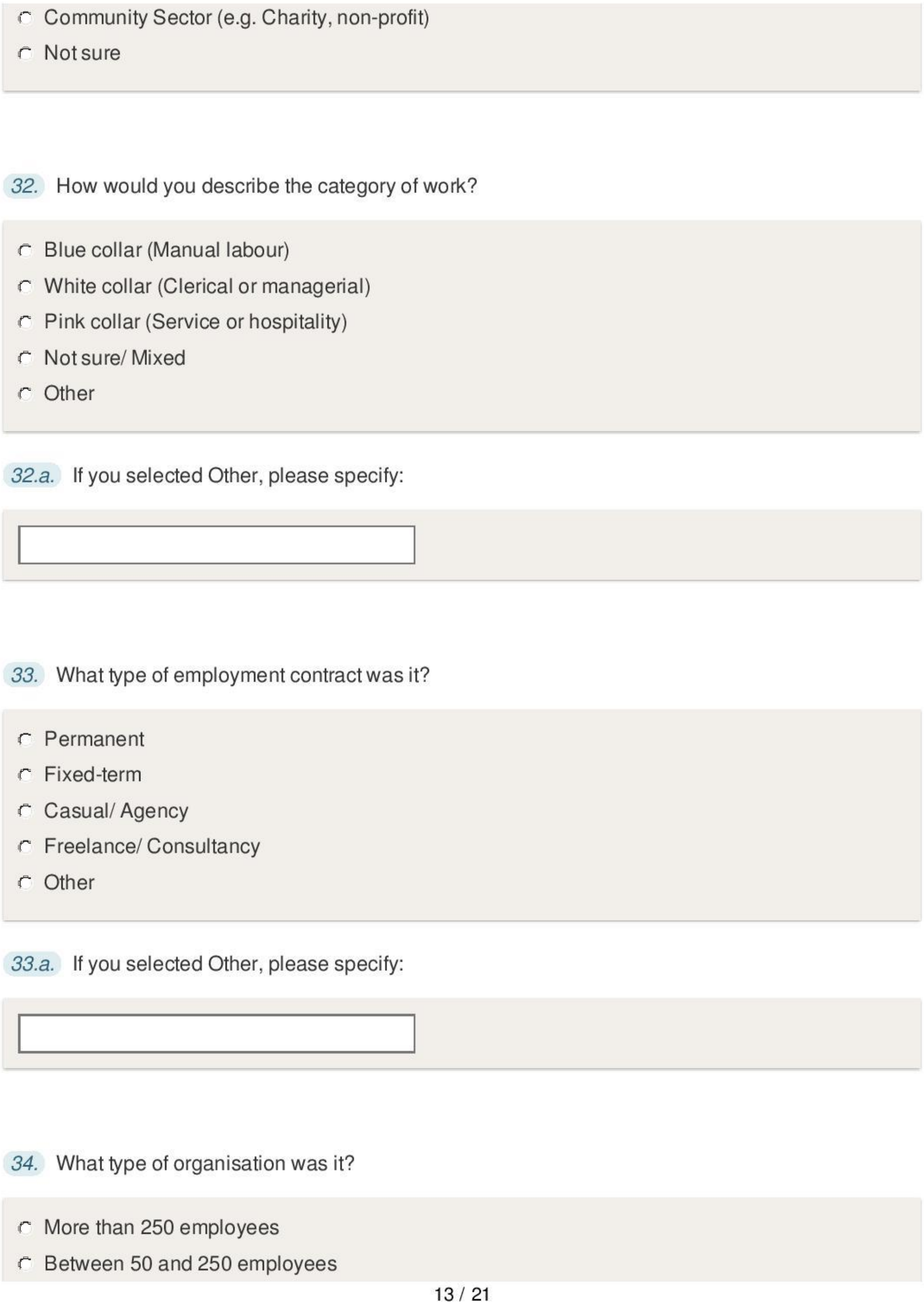
○ Yes - I want to return to work
○ No - I no longer feel I am able to work
○ Not sure / Undecided

29. What was your job title in the last position you held?

30. How long did you work for this employer?

31. What type of employment was it?

○ Public Sector (e.g. NHS, Council)
○ Private Sector



○ Community Sector (e.g. Charity, non-profit)
○ Not sure

32. How would you describe the category of work?

○ Blue collar (Manual labour)
○ White collar (Clerical or managerial)
○ Pink collar (Service or hospitality)
○ Not sure/ Mixed
○ Other

32.a. If you selected Other, please specify:

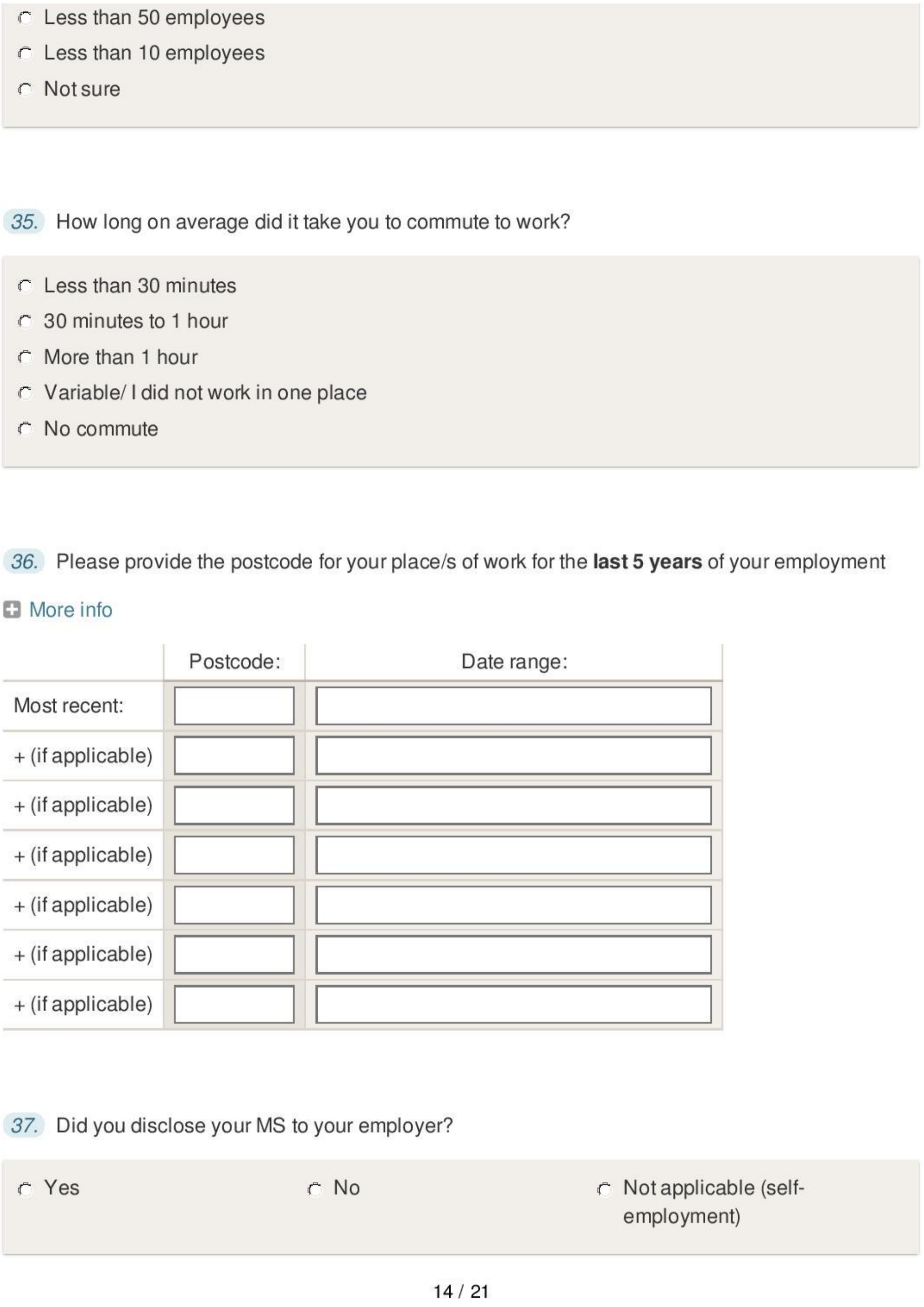
33. What type of employment contract was it?

○ Permanent
○ Fixed-term
○ Casual/ Agency
○ Freelance/ Consultancy
○ Other

33.a. If you selected Other, please specify:

34. What type of organisation was it?

○ More than 250 employees
○ Between 50 and 250 employees



○ Less than 50 employees
○ Less than 10 employees
○ Not sure

35. How long on average did it take you to commute to work?

○ Less than 30 minutes
○ 30 minutes to 1 hour
○ More than 1 hour
○ Variable/ I did not work in one place
○ No commute

36. Please provide the postcode for your place/s of work for the **last 5 years** of your employment

More info

	Postcode:	Date range:
Most recent:		
+ (if applicable)		
+ (if applicable)		
+ (if applicable)		
+ (if applicable)		
+ (if applicable)		
+ (if applicable)		

37. Did you disclose your MS to your employer?

○ Yes
○ No
○ Not applicable (self-employment)

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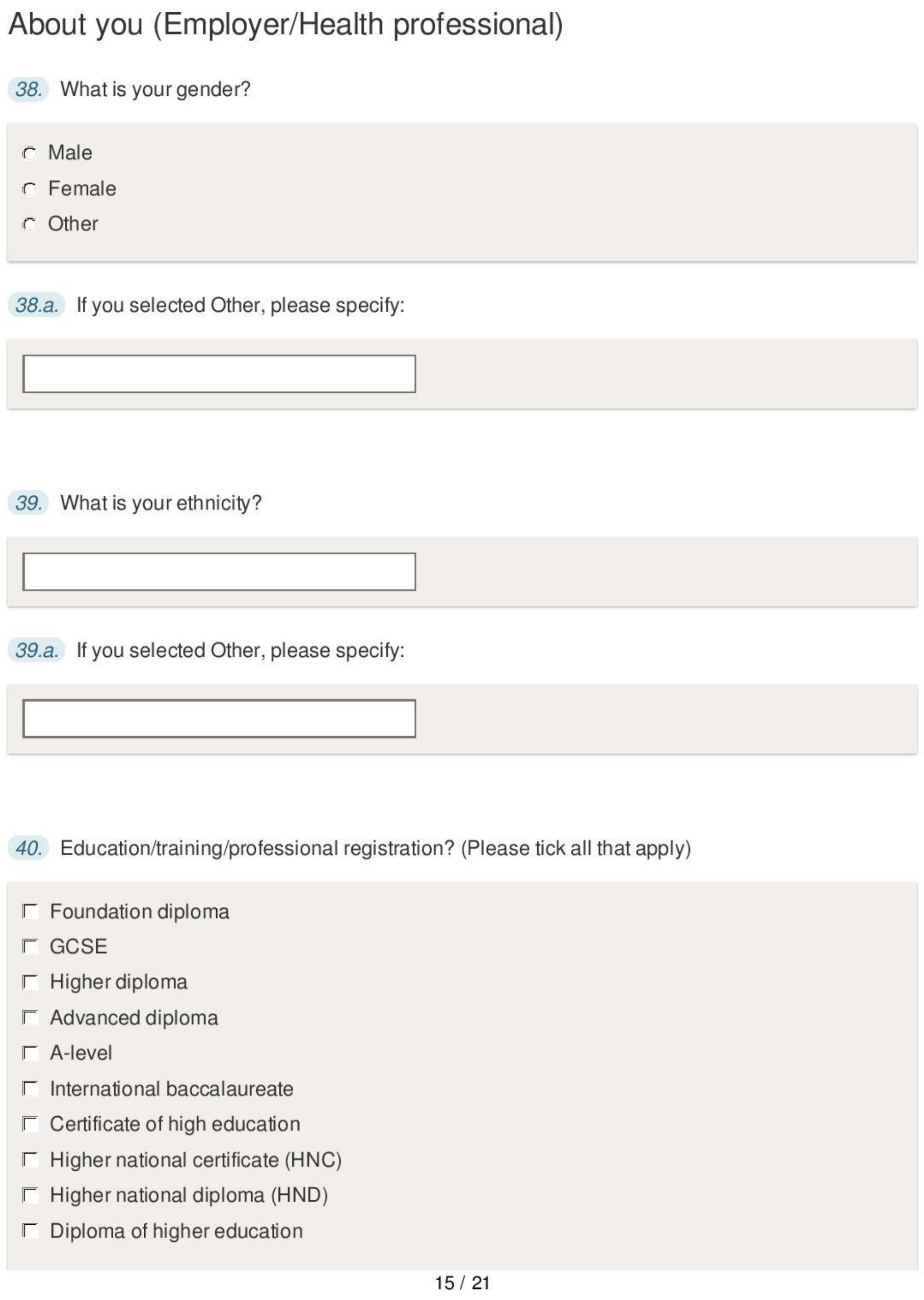


About you (Employer/Health professional)

38. What is your gender?

- ○ Male
- ○ Female
- ○ Other

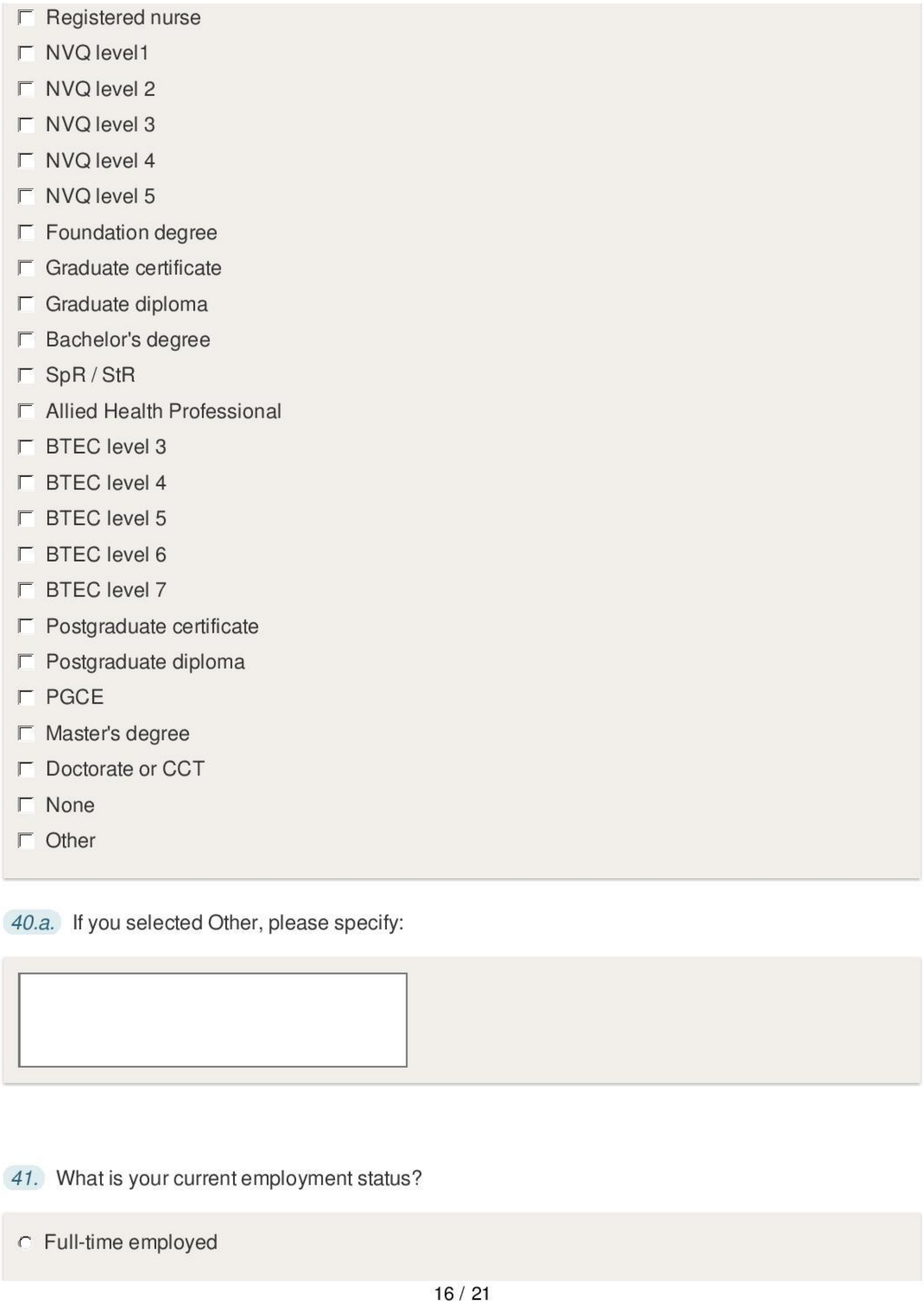
38.a. If you selected Other, please specify:

39. What is your ethnicity?

39.a. If you selected Other, please specify:

40. Education/training/professional registration? (Please tick all that apply)

- ☐ Foundation diploma
- ☐ GCSE
- ☐ Higher diploma
- ☐ Advanced diploma
- ☐ A-level
- ☐ International baccalaureate
- ☐ Certificate of high education
- ☐ Higher national certificate (HNC)
- ☐ Higher national diploma (HND)
- ☐ Diploma of higher education

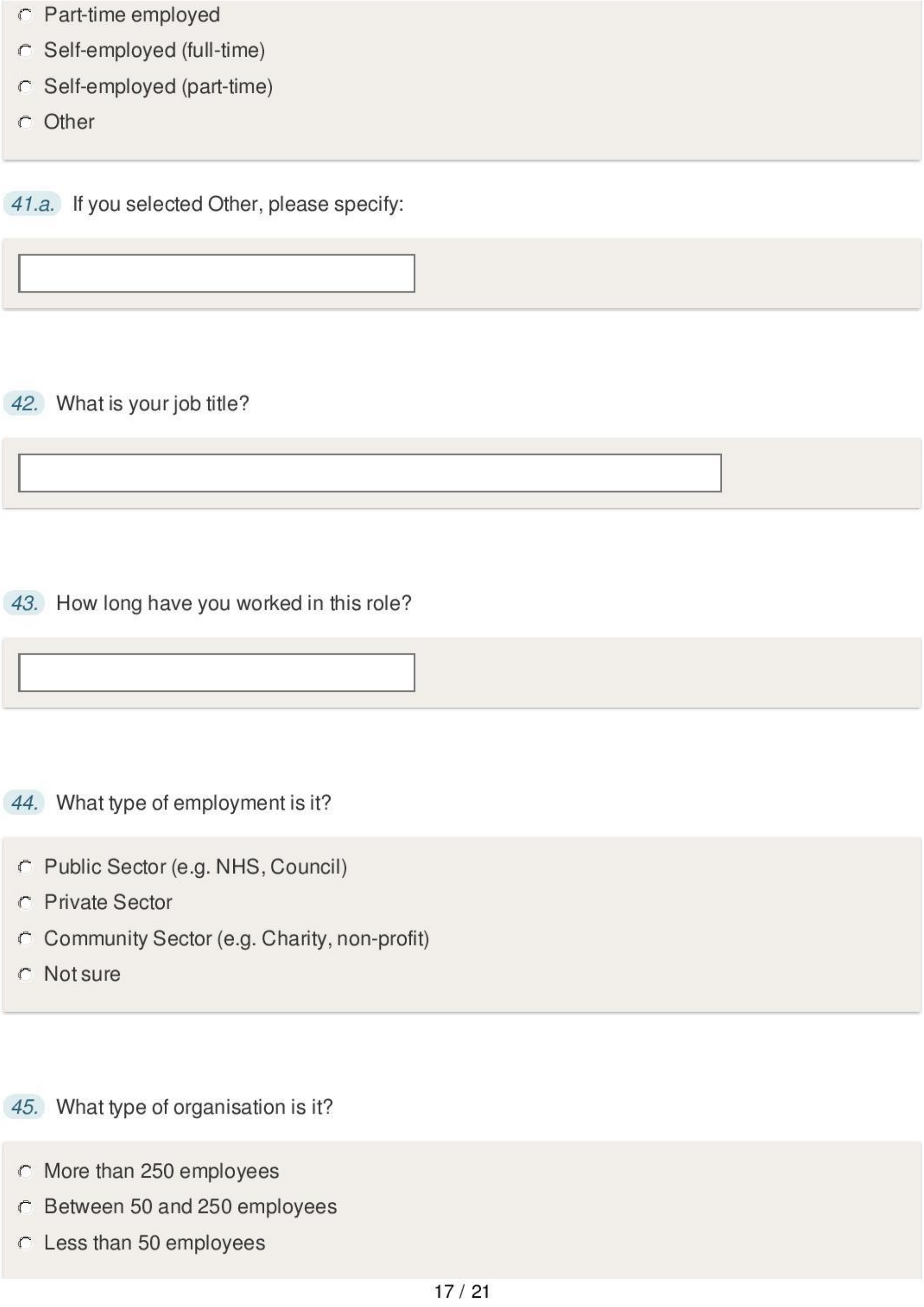


- ☐ Registered nurse
- ☐ NVQ level1
- ☐ NVQ level 2
- ☐ NVQ level 3
- ☐ NVQ level 4
- ☐ NVQ level 5
- ☐ Foundation degree
- ☐ Graduate certificate
- ☐ Graduate diploma
- ☐ Bachelor's degree
- ☐ SpR / StR
- ☐ Allied Health Professional
- ☐ BTEC level 3
- ☐ BTEC level 4
- ☐ BTEC level 5
- ☐ BTEC level 6
- ☐ BTEC level 7
- ☐ Postgraduate certificate
- ☐ Postgraduate diploma
- ☐ PGCE
- ☐ Master's degree
- ☐ Doctorate or CCT
- ☐ None
- ☐ Other

40.a. If you selected Other, please specify:

41. What is your current employment status?

- ○ Full-time employed



○ Part-time employed
○ Self-employed (full-time)
○ Self-employed (part-time)
○ Other

41.a. If you selected Other, please specify:

42. What is your job title?

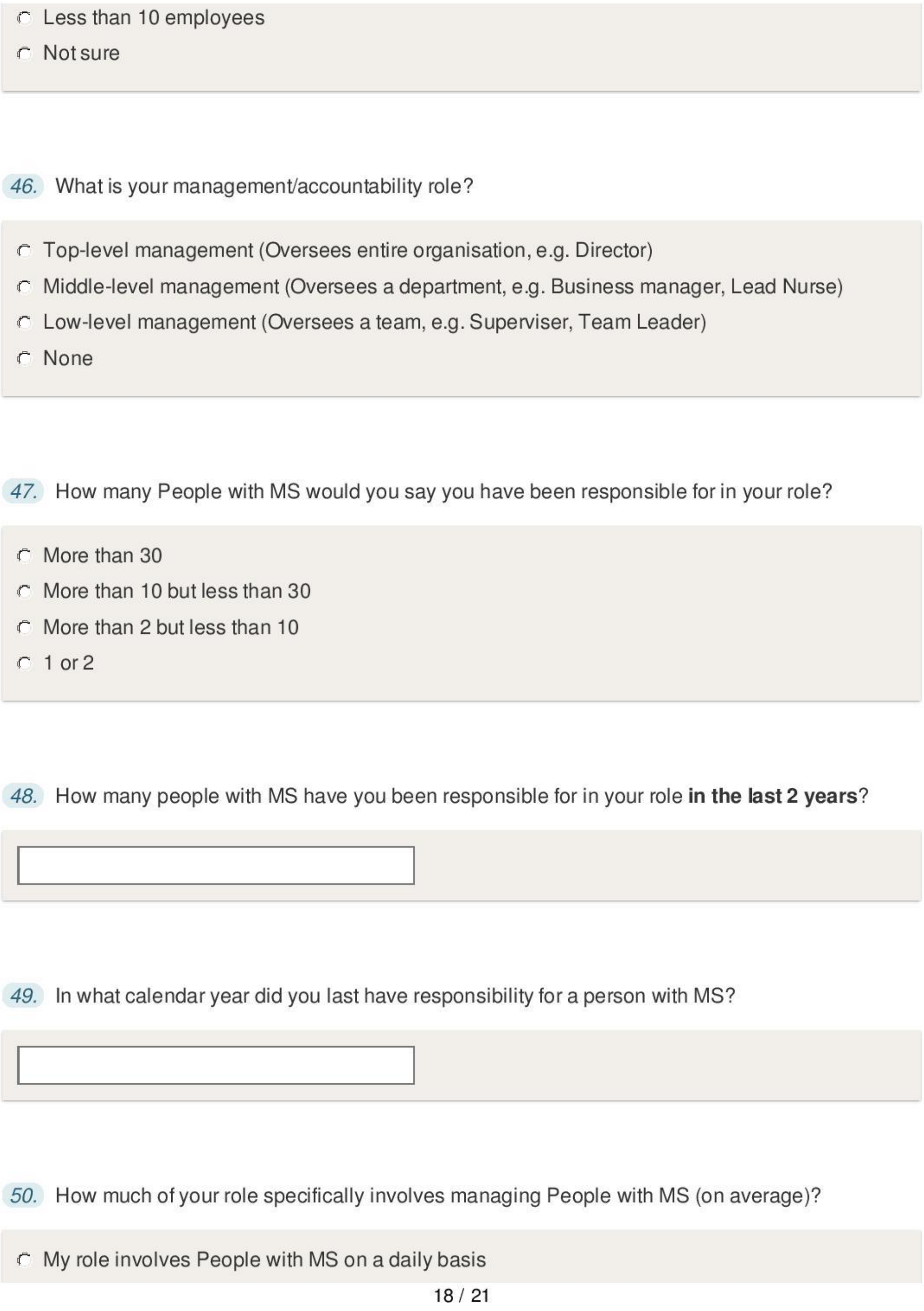
43. How long have you worked in this role?

44. What type of employment is it?

○ Public Sector (e.g. NHS, Council)
○ Private Sector
○ Community Sector (e.g. Charity, non-profit)
○ Not sure

45. What type of organisation is it?

○ More than 250 employees
○ Between 50 and 250 employees
○ Less than 50 employees



○ Less than 10 employees
○ Not sure

46. What is your management/accountability role?

○ Top-level management (Oversees entire organisation, e.g. Director)
○ Middle-level management (Oversees a department, e.g. Business manager, Lead Nurse)
○ Low-level management (Oversees a team, e.g. Superviser, Team Leader)
○ None

47. How many People with MS would you say you have been responsible for in your role?

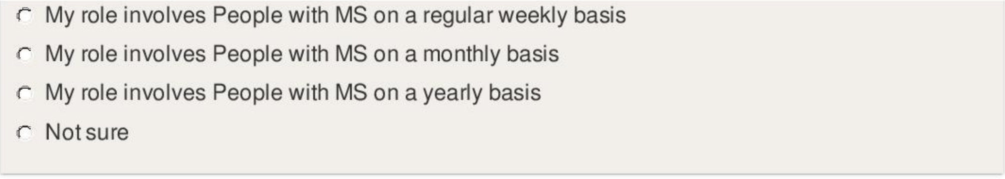
○ More than 30
○ More than 10 but less than 30
○ More than 2 but less than 10
○ 1 or 2

48. How many people with MS have you been responsible for in your role **in the last 2 years**?

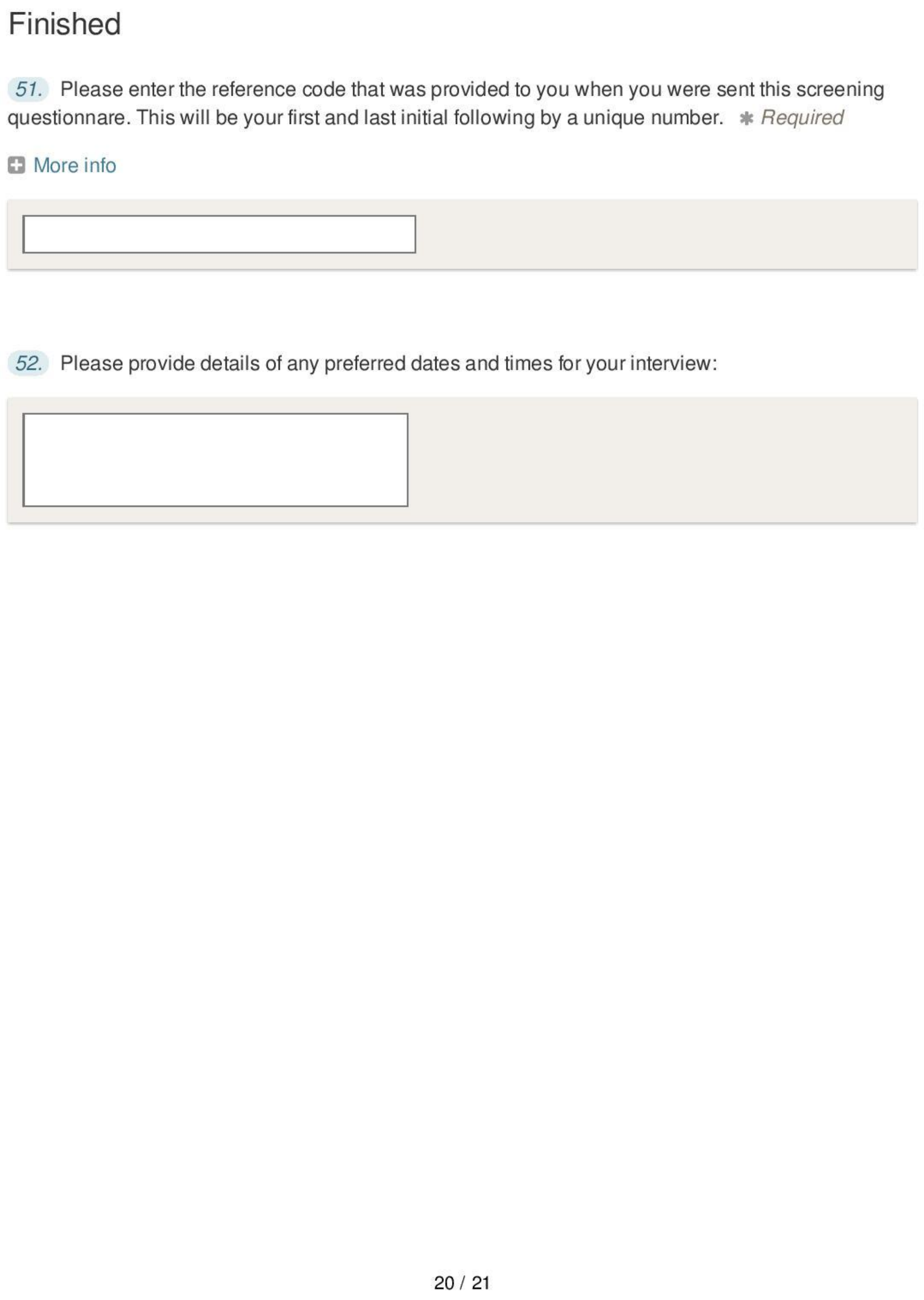
49. In what calendar year did you last have responsibility for a person with MS?

50. How much of your role specifically involves managing People with MS (on average)?

○ My role involves People with MS on a daily basis



○ My role involves People with MS on a regular weekly basis
○ My role involves People with MS on a monthly basis
○ My role involves People with MS on a yearly basis
○ Not sure



Finished

51. Please enter the reference code that was provided to you when you were sent this screening questionnare. This will be your first and last initial following by a unique number. ✱ *Required*

52. Please provide details of any preferred dates and times for your interview:

Thank you

Thank you for taking the time to complete this questionnaire.

If not already booked, the researcher will be in touch shortly to arrange a time and place for your interview convenient to you.

If you have any questions, please do not hesitate to contact the researcher, Charli Wicks by telphone on 0113 343 4283 or by email hs14crw@leeds.ac.uk

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Key for selection options

4 - What is your ethnicity?

Causasian (White)
Asian/ Asian British
Black/ African/ Caribbean/ Black British
Mixed/ Multiple Ethnic Groups
Other

39 - What is your ethnicity?

Causasian (White)
Asian/ Asian British
Black/ African/ Caribbean/ Black British
Mixed/ Multiple Ethnic Groups
Other

Appendix C – Interview Guides

Appendix C.1 –Data Set 1a (People with MS who are currently in work)

CHECK THE SCREENING QUESTIONNAIRE FOR CO-MORBIDY AND, IF ANY, REMEMBER TO ASK ABOUT THE IMPACT OF THESE CONDITIONS AND TO TRY TO UNPICK HOW THE SYMPTOMS INTERACTION OR DIFFERENTIALLY IMPACT THE INTERVIEWEE. SOME MODIFICATION OF THIS SCHEDULE WILL BE REQUIRED FOR THE SELF-EMPLOYED.

- Can you tell me how you first discovered that you have MS?
  - What were your first symptoms?
  - How long did it take you to get a diagnosis?
    - Did you have other illnesses or conditions at the time?
      - If yes: How did this impact you alongside the symptoms of MS?
  - Were you in employment at the time?
    - What job did you have then?
  - How did you manage your job while you were in the process of getting a diagnosis?
    - Did you experience any particular difficulties doing your job at the time?
    - Did anyone at work notice that you were having these difficulties?
      - If so, how did people react?
        - Your manager?
        - Your colleagues?
        - Your clients [or other people served]?
  - Are you in the same job now?
    - If no: is your change of job in any way related to having MS?
      - For example, did you change job to make it easier to remain in employment?

DEPENDING ON THE NUMBER OF JOBS WORKED IN SINCE DIAGNOSIS, ASK THE FOLLOWING FEW QUESTIONS ABOUT EACH EMPLOYER.

- Did you tell your employer that you had MS? / Does your current employer know that you have MS?
  - If no: Can you tell me why you decided not to disclose that you have MS?
  - If yes: Can you tell me how you went about telling your employer?
    - How did your employer respond to your disclosure?
  - Did/Do your colleagues know that you have MS?
    - How did they find out?
    - How did they respond to the news?
    - What impact has this had on you?
  - What about other people with whom you work(ed), such as clients [or other relevant people served] – did/do they know that you have MS?
    - How did they find out?
    - How did they respond to the news?

    - What impact has this had on you?

- Can you tell me **why** you have decided remain in paid employment since your MS diagnosis?
  - To what extent do you feel that you have a choice about remaining in paid work?
- What are the main challenges you have experienced remaining in work with MS?
  - To what extent are these challenges linked to the specific kind of work you do?
    - For example, how physically demanding the work is or how flexible the conditions….
  - To what extent are these challenges linked to the specific symptoms you have?
    - Symptoms of your MS?
      - Physical, cognitive, emotional symptoms….
    - If relevant: symptoms of any other conditions you have?
  - What positives have you found in having had to deal with these challenges?
  - What challenges you are still trying to overcome?
- What has helped you to stay in paid work following your MS diagnosis?
  - Has your diagnosis changed how you approach work?
    - Change or hours, change of working conditions, change of duties…
  - To what extent has your employer supported you to stay in work?
    - Can you tell me more about this?
      - To what extent has your manager been supportive?
      - What about people higher-up the organisation – have they been supportive?
      - What about Human Resources and Occupational Health – have they been supportive?
      - Have you consulted your Union in relation to any aspect of your MS?
        - Can you tell me more about this?
          - What issue did you consult them about?
          - What happened and what was the outcome?
      - Have you sought any legal advice related to working with MS?
        - Can you tell me more about this?
        - What knowledge do you have on legal policies regarding disability at work?
      - To what extent has your employer got good policies and procedures in place to support people in your situation?
    - To what extent have reasonable adjustments been made for you?
      - Can you tell me what adjustments have been made for you?
      - In what ways have these adjustments helped you?
    - Has your relationship with your employer changed since your diagnosis with MS?
    - What additional support would you like from your employer?
      - How would this additional support help you stay in work?
  - To what extent have your colleagues supported you?
    - Can you tell me more about this?

        - Has your relationship with colleagues changed since your diagnosis with MS?
            - If relevant: How have reasonable adjustments impacted your relationships with colleagues?
        - What additional support would you like from your colleagues?
        - How would this additional support help you stay in work?
    - How has your MS impacted your relationships with other people such as clients [and other relevant people served]?
        - If relevant: How have reasonable adjustments made in your work impacted your relationships with these people?
    - To what extent have health professionals supported you to stay in paid employment?
        - Can you tell me more about this?
        - What additional support would you like from health professionals?
        - How would this additional support help you stay in work?
    - What other potential sources of support have helped you stay in paid employment?
        - To what extent are you aware of government policies and requirements relevant to people with MS who are in paid employment?
            - Did you know where to find this kind of information?
        - Online information, support groups, family, friends…….
        - Can you tell me more about this?
        - Has your relationship with these people changed since your diagnosis with MS?
        - What additional support would you like from these other sources?
        - How would this additional support help you stay in work?
- What has been the impact on you of remaining in paid work with MS?
    - Have your feelings changed towards your job?
        - Can you tell me more about this?
    - Do you feel differently about yourself?
        - Can you tell me more about this?
    - Has your physical condition changed since your diagnosis?
        - Has your physical condition been impacted by your job?
        - Can you tell me more about this?
    - Has your psychological condition changed since your diagnosis?
        - For example: your memory, concentration, or mood?
        - Has your psychological condition been impacted by your job?
    - Has there been any positive affect of having had these experiences?
- Have you ever seriously considered withdrawing from paid employment?
    - Can you tell me about this?
        - What leads you to consider withdrawing from work?
        - How often does this happen?
        - What do you do when you have thoughts of withdrawing from work?
            - Do you discuss this with anyone?
            - What helps you best to cope with these thoughts of leaving work?
    - At what point do you think you will have to stop working?
        - For how long do you hope to be able to stay in paid employment?

            - To what extent do you think you will be able to keep working until normal retirement age?
        - How will you know that you need to stop working?
            - To what extent will you be glad to stop working?
        - Have you made plans for when you stop working?
            - Can you tell me more about this?
            - What are your hopes and fears for the future when you stop working?
                - What financial impact will this have on you?
- Having reflected on your experiences, is there anything this interview has raised that you think could be of benefit to discuss further with your employer?
- What advice would you give to someone just diagnosed with MS who wants to stay in paid employment?

Appendix C.2 – Data Set 1b (People with MS who have recently left work)

CHECK THE SCREENING QUESTIONNAIRE FOR CO-MORBIDY AND, IF ANY, REMEMBER TO ASK ABOUT THE IMPACT OF THESE CONDITIONS AND TO TRY TO UNPICK HOW THE SYMPTOMS INTERACTION OR DIFFERENTIALLY IMPACT THE INTERVIEWEE. SOME MODIFICATION OF THIS SCHEDULE WILL BE REQUIRED FOR THE SELF-EMPLOYED.

- Can you tell me how you first discovered that you have MS?
    - What were your first symptoms?
    - How long did it take you to get a diagnosis?
        - Did you have other illnesses or conditions at the time?
            - If yes: How did this impact you alongside the symptoms of MS?
    - Were you in employment at the time?
        - What job did you have then?
    - How did you manage your job while you were in the process of getting a diagnosis?
        - Did you experience any particular difficulties doing your job at the time?
        - Did anyone at work notice that you were having these difficulties?
            - If so, how did people react?
                - Your manager?
                - Your colleagues?
                - Your clients [or other people served]?
    - Did you change your job at any point after your received your MS diagnosis?
        - If yes: was your change of job in any way related to having MS?
            - For example, did you change job to make it easier to remain in employment?

DEPENDNG ON THE NUMBER OF JOBS WORKED IN SINCE DIAGNOSIS, ASK THE FOLLOWING FEW QUESTIONS ABOUT EACH EMPLOYER.

- Did you tell [any of] your employer[s] that you had MS?
    - If no: Can you tell me why you decided not to disclose that you have MS?
    - If yes: Can you tell me how you went about telling your employer[s]?

        - How did your employer[s] respond to your disclosure?
    - Did your colleagues know that you have MS?
        - How did they find out?
        - How did they respond to the news?
        - What impact did this have on you?
    - What about other people with whom you worked, such as clients [or other relevant people served] – did they know that you have MS?
        - How did they find out?
        - How did they respond to the news?
        - What impact did this have on you?

- What were the main challenges you experienced being employed while having MS?
    - To what extent were these challenges linked to the specific kind of work you had?
        - For example, how physically demanding the work was or how flexible the conditions….
    - To what extent were these challenges linked to the specific symptoms you have?
        - Symptoms of your MS?
            - Physical, cognitive, emotional symptoms….
        - If relevant: symptoms of any other conditions you have?
    - Have there been any positives to you having had to deal with these challenges?
    - To what extent do you feel your employer tried to support you to stay in work?
        - Can you tell me more about this?
            - To what extent was your manager supportive?
            - What about people higher-up the organisation – were they supportive?
            - What about Human Resources and Occupational Health – were they supportive?
            - Did you consult your Union in relation to any aspect of your MS?
                - Can you tell me more about this?
                    - What issue did you consult them about?
                    - What happened and what was the outcome?
            - Did you seek any legal advice related to working with MS?
                - Can you tell me more about this?
                - What knowledge do you have on legal policies regarding disability at work?
            - To what extent did your employer[s] have good policies and procedures in place to support people in your situation?
        - To what extent were reasonable adjustments made for you?
            - Can you tell me what adjustments were made for you?
            - In what ways did these adjustments help you?
        - Did your relationship with your employer change at all following your diagnosis with MS?
        - What additional support would you have liked from your employer?
            - How would this additional support have helped you to stay in work?

  - To what extent did your colleagues support you?
    - Can you tell me more about this?
    - Did your relationship with colleagues change since your diagnosis with MS?
      - If relevant: How did reasonable adjustments impact your relationships with colleagues?
    - What additional support would you have liked from your colleagues?
    - How would this additional support have helped you to stay in work?
  - How did your MS impact your relationships with other people such as clients [and other relevant people served] at work?
    - If relevant: How did reasonable adjustments made in your work impact your relationships with these people?
  - To what extent did health professionals try to support you to stay in paid employment?
    - Can you tell me more about this?
    - What additional support would you have liked from health professionals?
    - How would this additional support have helped you stay in work?
  - What other potential sources of support might have helped you to stay in paid employment?
    - To what extent are you aware of government policies and requirements relevant to people with MS who are in paid employment?
      - Did you know where to find this kind of information?
    - Online information, support groups, family, friends…….
    - Can you tell me more about this?
    - Has your relationship with these people changed since your diagnosis with MS?
    - What additional support would you like from these other sources?
    - How would this additional support have helped you to stay in work?
- Can you tell me what led to you leaving paid employment?
  - To what extent do you feel that you had a choice about leaving paid work?
  - How long did it take from first considering withdrawing from work to actually leaving?
  - What support did you have during withdrawal from work?
      - What helped you best to cope with the experience of leaving work?
  - Do you think you could have continued to work for longer than you did?
    - What would have helped you to keep working for longer than you did?
      - To what extent are you glad to have stopped working?
- What has been the impact on you of leaving paid employment?
  - Have your feelings changed towards your previous job since leaving work?
    - Can you tell me more about this?
  - Do you feel differently about yourself?
    - Can you tell me more about this?
  - Has your physical condition changed since leaving work?
    - Has your physical condition been impacted by your previous job[s]?
    - Can you tell me more about this?
  - Has your psychological condition changed since leaving work?
    - For example: your memory, concentration, or mood?

        - Has your psychological condition been impacted by your previous job[s]?
    - Has there been any positive affect of having had these experiences?
    - What are your plans now that you have stopped working?
        - Have these plans changed since you first considered withdrawing from work?
        - What are your hopes and fears for the future now that you have stopped working?
            - What financial impact will this have on you?
- What advice would you give to someone just diagnosed with MS who wants to stay in paid employment?
- What advice would you give to someone with MS considering leaving paid employment?

Appendix C.3 –Data Set 2 (Health Professionals relevant to PwMS)

- To what extent does your role as a health professional involve working with people with MS?
    - Can you tell me a bit about what your job involves when your patient has MS?
- Would you always know if an MS patient you were treating was in paid employment?
    - If yes: Can you tell me how would you know this information?
    - All answers: Do you think this is important for you to know?
        - Can tell me why that is?
        - What use could you make of this information?
- Who do you think is responsible for supporting people with MS to stay in paid employment?

The following questions are about your patients with MS who are in paid employment or who have recently left paid employment.

- Do you see it as part of your role to discuss with your MS patients how they are managing at work?
    - If no: Can you tell me a bit more why this is outside your remit?
    - If yes: Can you tell me a bit more why this is relevant to your role as a health professional working with people with MS?
    - Do you always ask your MS patients how they are getting on at work?
- Is employment a topic that your MS patients raise with you?
    - What kind of issues do they raise with you about their work?
- To what extent do you MS patients appear to want to remain in paid employment?
    - Why is that do you think?
- What are the main challenges your patients experience remaining in work with MS?
    - To what extent are these challenges linked to the specific kind of work they do?
        - For example, how physically demanding the work is or how flexible the conditions….
    - To what extent are these challenges linked to the specific symptoms they have?
        - Symptoms of your MS?
            - Physical, cognitive, emotional symptoms….
        - If relevant: symptoms of any other conditions they have?
- What tends to helped people with MS to stay in paid work?
    - For example, do they have to change the way they approach work?

        - Change or hours, change of working conditions, change of duties…
- Do you think your MS patients should tell their employer that they have MS?
    - Can you tell me a bit more why you think that?
        - What are the possible benefits of disclosure?
        - What are the possible downsides of disclosure?
- Do you think your MS patients should tell their work colleagues that they have MS?
    - Can you tell me a bit more why you think that?
        - What are the possible benefits of disclosure?
        - What are the possible downsides of disclosure?
- To what extent do employers appear to support people with MS to stay in work?
    - Can you tell me more about this?
    - To what extent does this vary between employers?
            - To what extent do managers appear to be supportive?
            - What about people higher-up the organisation – do they appear to be supportive?
            - What about Human Resources and Occupational Health – do they appear to be supportive?
            - Are you aware of any of your patients with MS having consulted their work Union in relation to any aspect of their MS?
                - Can you tell me more about this?
                    - What issue did they consult them about?
                    - What happened and what was the outcome?
            - To what extent do employers have good policies and procedures in place to support people with MS?
        - To what extent are reasonable adjustments made for people with MS in the workplace?
            - Can you tell me what adjustments have been made for some of your patients with MS?
            - In what ways have these adjustments helped these patients?
        - What additional support would you like to see from employers for people with MS?
            - How would this additional support help people with MS to stay in work?
    - To what extent do work colleagues appear to be supportive of people with MS in the workplace?
        - Can you tell me more about this?
        - What additional support would you like to see from colleagues for people with MS with whom they work?
        - How would this additional support help people with MS to stay in work?
    - To what extent can health professionals support people with MS to stay in paid employment?
        - Can you tell me more about this?
    - What other potential sources of support can help people with MS to stay in paid employment?
        - The government?

        - Online information, support groups, family, friends…….
        - Can you tell me more about this?
        - What additional support would you like to see from these other sources?
        - How would this additional support help people with MS to stay in work?
- Do you ever need to advise a patient with MS about changing job because of their MS?
    - What would be the reason for giving this advice?
    - For example: legal and or safety reasons, particular symptoms making the job difficult…..
- What is the impact on a person with MS of remaining in paid employment?
    - On how they feel about themselves?
    - On their physical condition?
    - On their psychological condition?
        - For example: memory, concentration, or mood?
    - Financially?
- Do you ever need to advise a patient with MS to consider withdrawing from paid employment?
    - Can you tell me about this?
        - At what point do you think someone with MS needs to consider withdrawing from paid employment?
            - To what extent do you think someone with MS should be able to keep working until normal retirement age?
- What plans should people with MS make for when they stop working?
            - Can you tell me more about this?
- To what extent have you had access to adequate support and training to help you advise patients with MS about staying in work?
    - What support and training have you found particularly useful?
    - What (additional) support and training would you liked to receive?
- To what extent are you aware of government policies and requirements relevant to people with MS who are in paid employment?
    - Did you know where to find this kind of information?
- In summary, what advice would you give to healthcare providers who are trying to support their patients with MS to stay in paid employment?

Appendix C.4 –Data Set 3 (Employers relevant to PwMS)

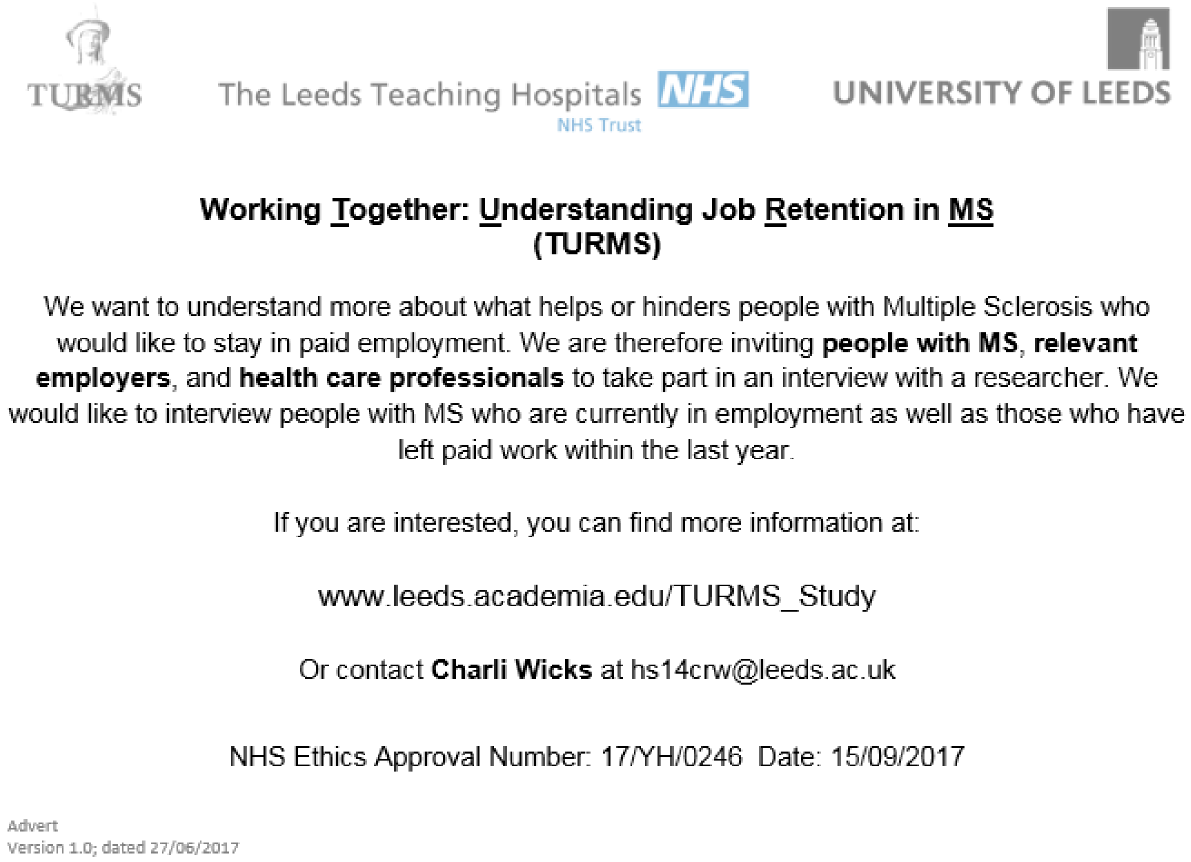
Make clear before starting the interview that, for reasons of confidentiality, the real name of any person with MS should not be used. If acceptable, a false name could be used or just the pronouns he/she/they.

- Can you tell me a bit about your role?
    - Does your role involve discussing health related issues with the people you manage or supervise?
    - To what extent has your role involved managing or supervising people with MS?
    - Do you think it important for you to know if someone you manage or supervise has MS?

        - Can tell me why that is?
        - What use could you make of this information?
- Can you tell me how you came to find out that X (and Y) have MS?
    - Did you suspect that anything was wrong before you found out?
        - If yes: What made you suspect something?
            - What did you do?
- Do you think that employees should always tell their employer if they have MS?
    - Can you tell me a bit more why you think that?
    - What are the possible benefits of disclosure?
    - What are the possible downsides of disclosure?
- What was your first reaction when you found out that X (and Y) have MS?
    - How did they seem to be coping with the diagnosis themselves?
    - How did they seem to be coping at work at that time?
    - As their manager/supervisor what did you do with this information?
        - Did you know if you needed to provide any support?
        - Did you ask anyone at your work for information about what to do?
        - Did you know how to find out what to do?
        - To what extent does your organisation have policies and procedures in place to support people with MS?
            - How helpful were these policies and procedures?
- Who do you think is responsible for supporting people with MS to stay in paid employment?
    - Can you tell me why you think this?
- To what extent are you able to support the people with MS you manage or supervise to stay in work?
    - What were the main challenges to supporting X (and Y)?
    - To what extent are these challenges linked to the specific kind of work they do?
        - For example, how physically demanding the work is or how flexible the conditions….
    - To what extent are these challenges linked to the specific symptoms X (and Y) experienced?
        - Physical, cognitive, emotional symptoms….
- How did you deal with these challenges?
    - For example, did you have to support X (and Y) to change the way they approach work?
    - Change of hours, change of working conditions, change of duties…
    - Were any ‘reasonable adjustments’ made?
        - Can you tell me what adjustments were made?
        - In what ways have these adjustments helped?
    - What additional support would you like to be able to offer people with MS?
        - How would this additional support help people with MS to stay in work?
        - What stops you being able to offer this support?
- To what extent was your own manager helpful to you in providing support to X (and Y)?
    - Can you tell me a bit more about this?
        - What about people higher-up the organisation – were they helpful?
            - Can you tell me a bit more about this?
        - What about Human Resources and Occupational Health – were they helpful?

      - Can you tell me a bit more about this?
  - What about the Union – were they helpful?
    - Can you tell me a bit more about this?
- Are you aware if X (and Y) consulted their work Union in relation to any aspect of their MS?
  - Can you tell me more about this?
  - What issue did they consult them about?
  - What happened and what was the outcome?
- Are you aware if X (and Y) consulted sought any legal advice related to working with MS?
  - Can you tell me more about this?
  - What knowledge do you have on legal policies regarding disability at work?
-
- To what extent have X (and Y's) colleagues been supportive of them?
    - Can you tell me more about this?
    - What additional support for X (and Y) would you like to see from colleagues?
    - How would this additional support help X (and Y) to stay in work?
- Do you think that employees should always tell their work colleagues if they have MS?
  - Can you tell me a bit more why you think that?
  - What are the possible benefits of disclosure to colleagues?
  - What are the possible downsides of disclosure to colleagues?
- What other potential sources of support can help people with MS to stay in paid employment?
  - The government?
  - Online information, support groups, family, friends…….
    - How would this additional support help people with MS to stay in work?
    - What additional support would you like to see from these other sources?
- At what point do you think someone with MS needs to consider withdrawing from paid employment?
  - Have you ever needed to have this discussion with X (and Y)?
  - Can you tell me about this?
- To what extent have you had access to adequate support and training to help you support employees with MS to stay in work?
  - What support and training have you found particularly useful?
  - What (additional) support and training would you liked to receive?
- To what extent are you aware of government policies and requirements relevant to people with MS who are in paid employment?
  - Did you know where to find this kind of information?
- In summary, what advice would you give to employers who are trying to support their employees with MS to stay in paid employment?

Appendix D – Study Advertisement



TURMS The Leeds Teaching Hospitals NHS NHS Trust UNIVERSITY OF LEEDS

Working Together: Understanding Job Retention in MS
(TURMS)

We want to understand more about what helps or hinders people with Multiple Sclerosis who would like to stay in paid employment. We are therefore inviting **people with MS**, **relevant employers**, and **health care professionals** to take part in an interview with a researcher. We would like to interview people with MS who are currently in employment as well as those who have left paid work within the last year.

If you are interested, you can find more information at:

www.leeds.academia.edu/TURMS_Study

Or contact **Charli Wicks** at hs14crw@leeds.ac.uk

NHS Ethics Approval Number: 17/YH/0246 Date: 15/09/2017

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