UNIVERSITY OF BIRMINGHAM

SCHOOL OF SPORT, EXERCISE AND REHABILITATION SCIENCES

A qualitative and quantitative exploration of sedentary behaviour, physical activity and exercise in people with multiple sclerosis

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November 2021

A thesis submitted to the University of Birmingham for the degree of
Doctor of Philosophy

School of Sport, Exercise and Rehabilitation Sciences
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ABSTRACT

Multiple sclerosis (MS) is a chronic neurological disease affecting motor and sensory nerve function and leading to a range of symptoms. Physically, gait, balance and vision can be impaired, with fatigue and depression being common mental health symptoms. People with MS have high levels of sedentary behaviour and low levels of physical activity. Despite the well-researched benefits of exercise for the symptoms of MS, uptake and participation in exercise programmes is low, particularly in those with higher disability. This thesis investigated a number of research questions relating to activity behaviours in people with MS using both qualitative and quantitative methodologies. Qualitative studies explored the measurement of sedentary behaviour, and perspectives of people with MS and health professionals around barriers and facilitators to exercise. This provided recommendations for exercise programmes. Communication was a key aspect, which included communication to the person with MS tailored to their individual circumstances and acceptance of MS, as well as communication within the multidisciplinary team. Appropriate knowledge of health professionals about exercise for people with MS was essential as well as suitable behavioural support for exercise. This support should be individualised to the patient, depending on their stage of acceptance of the disease. Cross-sectional analyses of associations between subjective and objective assessments of behaviour, physical function, and wellbeing revealed differences, such as objective but not subjective sedentary behaviour being associated with depression. Greater self-reported but not objective physical activity was associated with higher fitness. This highlighted the need to assess activity and function both subjectively and objectively. Subsequently, the effects of a twelve-week home exercise programme which included balance, strengthening and aerobic exercise, on physical activity, sedentary behaviour, functional ability, and wellbeing were explored. The outcomes of those with higher and lower disability from their MS were compared, as well as an internet group with access to web-based resources to support their programme, and a control group without these online resources. The exercise programme achieved good self-reported adherence. However, there were no significant changes in physical activity, function, wellbeing or behavioural measures, which suggests that more intensive behavioural support might be needed to ensure that participants exercise at the right intensity. Future research could investigate the effectiveness of different ways to provide additional support to encourage exercise in people with MS.

ACKNOWLEDGEMENTS

My first thanks go to my supervisors, Dr Jet Veldhuijzen van Zanten, and Professor Michael Douglas for their continued help and advice. Both of you have helped me immensely to develop my knowledge, and my skills as a researcher and as a writer. You have both put in extra time to support me, particularly in recent months on top of an already increased workload, and I will always be grateful for this. Dr Elizabeth Hale has also been an essential part of the qualitative research team. Thank you Liz, for sharing your enthusiasm for qualitative research, for asking the difficult questions and challenging me throughout the analysis process. Dudley Group of Hospitals, where I undertook the research has an excellent support team and I thank Margaret Marriott, Claire Phillips and others in the research office at Russell's Hall, as well as Jacqueline and Jan in the laboratory for their help. I also thank the support team at Dudley Guest, and particularly Tracy Dean, MS Specialist nurse for her assistance throughout with participant recruitment.

Thanks also go to the participants of my studies, firstly the people with MS and health professionals who generously gave up their time to share their views with me. I also particularly thank the people who volunteered to take part in the exercise programme. I was continually inspired by your determination, despite living with the daily uncertainty of this condition, and I learnt something new from every one of you.

My colleagues at the University of Birmingham have been an unending support also and I especially thank Christina Anderson, a long-time friend and office mate for her encouragement, and the good coffee. Also my physiotherapy PhD colleagues who have offered useful advice all the way through, Sheeba Rosewilliam, Nicola Heneghan, Ali Rushton, Jill Ramsay, Mel Stewart and David Punt.

Many friends have inspired me to follow this path and I thank in particular Laura Leslie, Nicola Cumley and Rajinder Mann. All of you got through the PhD long before me and all of you have encouraged me to keep going, and have helped me in too many ways to mention. I'm also grateful as ever to my wonderful family – heartfelt thanks to my amazing parents, I can't really do justice to the support you have given me always. Also I thank my siblings Chandra and Ravi, and the extended siblings Simon and Izzy, and the niblings Reuben and Nia. I know I can count on you for anything at all, the distractions and the light relief have been very welcome.

My biggest thanks go to Paul, who inspired me back in 2005 with a PhD of his own, never stopped believing in me and who has been there every day. I know there have been sacrifices to family life in recent times and I hope I can make up for these in the years to come. And finally to Octavia, who

has brought so much joy into our lives since she arrived in August 2019, and in whom I hope I can inspire an enquiring mind and to strive for the goals she chooses in life.

PUBLICATIONS AND CONFERENCE PAPERS

Hensman M, 2017, Exercise in Multiple Sclerosis, In Touch (Physio First), Spring 2017, 16-20. *(Journal article)*

Hensman M, Pilutti L, Motl R, Fenton S, Duda J, Douglas M, Veldhuijzen van Zanten J, 2017, Sedentary Behaviour in Multiple Sclerosis – Assessment and Implications, World Confederation of Physical Therapy Congress, Cape Town, South Africa.*(Platform presentation)*

Hensman M, Motl R W, Pilutti L A, Fenton S A M, Duda J A, Douglas M, Veldhuijzen van Zanten J J C S, 2019, Comparison of sedentary behaviour questionnaires in people with multiple sclerosis, Disability and Rehabilitation, DOI: 10.1080/09638288.2019.1597179 *(Journal article)*

Perceptions of exercise - what moves people with multiple sclerosis to exercise?, Hensman M, Veldhuijzen van Zanten J, Hale E, Douglas M, 2019, Third International Congress on Neurorehabilitation and Neural Repair, Maastricht, Netherlands. *(Platform presentation)*

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CHAPTER 1: GENERAL INTRODUCTION: MULTIPLE SCLEROSIS

1.1 WHAT IS MS?

Multiple sclerosis (MS) is a chronic auto-immune condition characterised by demyelination of the central nervous system. MS can cause problems with both the motor and sensory functions of nerves, leading to impairments to vision, gait, cognition, sensation, balance and bowel and bladder function (Brownlee et al., 2017). The presentation of MS is variable with symptoms differing from person to person.

This chapter will provide an overview of the background to MS, its symptoms and co-morbidities, and treatment through both medications and alternative methods including physical activity and exercise. Given the focus of the thesis on sedentary behaviour, physical activity, and exercise, the introduction will also include an overview of the effects of these behaviours on the symptoms of MS and ways to encourage changes in behaviour.

1.1.1 EPIDEMIOLOGY

MS affects approximately 2.3 million people worldwide, mainly in temperate climates (Browne et al 2014), including around 127 000 people in the UK (Mackenzie et al., 2014). This equates to a worldwide prevalence of 30.1 cases per 100 000 people (Wallin and al., 2019). Females are more likely to be affected than males, accounting for 72% of prevalent cases (Mackenzie et al., 2014). The onset of symptomology is usually in early adulthood, typically occurring between the ages of 20 and 40 years (Ford, 2020).

1.1.2 AETIOLOGY

The cause of MS is not known. However, there are a number of known risk factors which appear to increase incidence rates. These are detailed below:

i) Genetic factors: Incidence rates of MS increase if a parent or sibling is affected (Compston and Coles, 2008).

ii) Environmental risk factors: Cigarette smoking is a known risk factor, linked to a 50% greater risk for MS (Salzer et al., 2012). Longer duration and higher levels of cigarette smoking increase the risk of developing MS, particularly for men (Thompson et al., 2018a). Vitamin D deficiency is another significant risk factor for MS. This is linked to reduced sunlight exposure, and lack of natural vitamin D production in darker skinned ethnic groups (Thompson et al., 2018a).

iii) Infection: Numerous studies and meta-analyses have reported that over 98% of adults with MS tested positive for prior Epstein Barr virus infection (Pakpoor et al., 2012), suggesting that this could be a pre-cursor to the development of MS.

iv) Geographical location: The population of people with MS tends to increase with distance away from the equator. The highest prevalences are reported in the USA, Europe, Australia, and New Zealand at >100 cases per 100 000 people (Browne et al., 2014).

1.1.3 PATHOGENESIS

In a healthy central nervous system, myelin is a fatty substance which surrounds nerve cells, providing them with an insulating layer to increase nerve conduction velocity and efficiency. Myelin also provides structure and metabolic protection to the nerve axon (Figure 1.1).

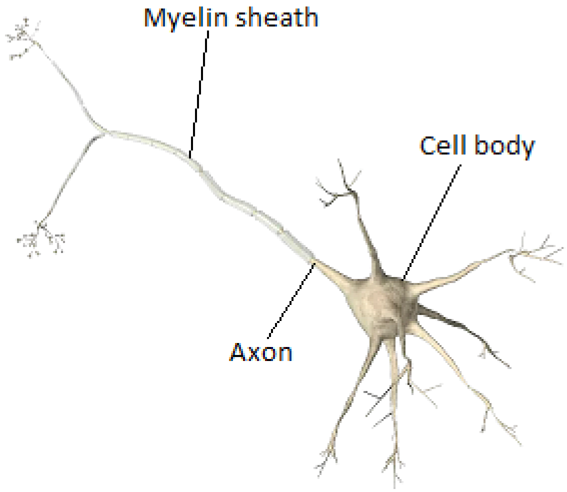


Figure 1.1: Structure of a neurone (Primal Pictures 2018)

In MS, nerve conduction is impaired due to myelin sheaths being damaged in a process known as demyelination. Antigens specific to the central nervous system (CNS) are detected by the T cells and B cells of the immune system (Thompson et al., 2018b), which leads to a pathogenic auto-immune inflammatory response resulting in demyelination. An alternative cause for inflammation is via primary degeneration of axons and the oligodendrocytes which make up the myelin, without immune cell involvement (Palumbo, 2017). Commonly affected regions of the nervous system are the spinal cord, optic nerves, cerebellum, and cerebral cortex (Brownlee and Miller, 2014). Demyelination leads to a range of neurological symptoms depending on the site of the CNS involved. The inflammatory phase is followed by a phase of repair and recovery, in which some of the lost functions of the nerve may return. Areas of acute inflammation can be detected radiologically as areas of gadolinium enhancement on brain and spinal cord magnetic resonance imaging (MRI) (Thompson et al., 2018b). Cycles of damage and repair can lead to permanent destruction of the axon. The end result of the inflammatory processes is the presence of white matter plaques or areas of scarring (gliosis) which are key characteristics of this condition, particularly in established disease.

1.2 DIAGNOSIS AND TYPES OF MS

Symptoms of MS vary from person to person and cover a range of domains of physical and psychological function as mentioned previously. Symptoms in a person with multiple sclerosis can be relapsing or progressive (Brownlee et al., 2017). 80% of patients present with a first acute episode, referred to as a clinically isolated syndrome (CIS), affecting one or more sites (Compston and Coles, 2008). Common early symptoms include unilateral optic neuritis, myelitis or a brainstem syndrome (Brownlee and Miller, 2014). Symptoms present in a similar way to an MS relapse, developing over hours to days, with a peak after two to three weeks (Brownlee and Miller, 2014). Two thirds of those presenting with a CIS will go on to develop relapsing-remitting MS. An MRI scan of the brain and also the spinal cord, the latter if symptoms indicate possible spinal lesions, is recommended to detect the presence of MS plaques (Thompson et al., 2018a).

1.2.1 DIAGNOSIS

A diagnosis of MS may not be made at first onset of symptoms, as evidence of CNS lesions both disseminated in space and time are needed (Polman et al., 2011). Dissemination in space is shown by at least one lesion in at least two of four characteristic locations (spinal cord, infratentorial, periventricular and juxtacortical) (Polman et al., 2011). Dissemination in time is usually demonstrated by the presence of a new lesion on a follow-up MRI scan (Polman et al., 2011). Diagnosis is made by a neurologist based on the neurological examination combined with imaging and other supportive tests (Thompson et al., 2018a). These may include a lumbar puncture, to test the cerebrospinal fluid for raised immunoglobulin G or oligoclonal bands, either of which suggest inflammation of the nervous system (Polman et al., 2011). If there is a history of visual disturbance suggesting possible optic nerve involvement, testing may include visual evoked potentials (Polman et al., 2011).

There are three main clinical patterns of MS, which will be described below.

1.2.2 RELAPSING-REMITTING MS

The most common type of MS is relapsing-remitting, affecting 85 – 90% of patients. This type of MS is characterised by the occurrence of relapses, defined as an acute onset of new or worsening neurological symptoms in the absence of fever or infection (Berkovich, 2016). The relapse is followed by a period of remission which can last months to years, where significant remyelination and recovery of lost function occurs. Relapsing remitting MS affects younger adults, with a mean age of onset of 30 years (Brownlee et al., 2017). Over time, recovery from relapses becomes less complete, leading to a progression of disability (Doshi and Chataway, 2016), usually termed secondary progressive disease.

1.2.3 PRIMARY PROGRESSIVE MS

Primary progressive MS affects 10-15% of those diagnosed with MS. In this situation there is a steady decline in neurological function, without evident periods of relapse and remission. Primary progressive MS patients usually present with their first symptoms at an older age (mean 40 years) than those with relapsing remitting disease (Brownlee et al., 2017).

1.2.4 SECONDARY PROGRESSIVE MS

Secondary progressive MS is diagnosed when a patient initially presents with relapsing remitting disease but the periods of remission decline, and the disease gradually follows a progressive course. Up to 80% of those first diagnosed with relapsing remitting MS will develop secondary progressive disease within 10–15 years of onset (Doshi and Chataway, 2016).

Medical treatment differs depending on the type of MS and symptoms to be addressed. For relapsing-remitting MS, treatment may be needed to assist in the recovery from an acute relapse. A range of disease modifying therapies (DMT’s) are also available (Thompson et al., 2018b). These drugs modulate the immune response in MS, for example reducing the influx of T and B cells into the CNS. This has the effect of reducing the number and severity of relapses (Doshi and Chataway, 2016). For those with progressive forms of MS there are more limited options, for example anti CD20 monoclonal antibody treatment Ocrelizumab (Thompson et al., 2018b). Both relapsing and progressive groups may be offered medication to treat symptoms of their condition for example pain or spasticity. Medication will be discussed further later in this chapter.

1.2.5 DISEASE ACTIVITY

In addition to their type of MS, disease activity is also an important factor in the impact of the condition on the individual. A person is described as having active MS if they present with symptoms of relapse, or their MRI scan shows new lesions over a defined interval (Doshi and Chataway, 2016). Due to recent advances in medical treatments for MS, patients can now be categorised as having no evidence of disease activity (NEDA) if they suffer no relapses, progression of their disability or MRI lesions (Thompson et al., 2018b). Patterns of disease activity can assist in decisions guiding the prescription of disease modifying therapies.

1.3 CLASSIFICATION OF DISABILITY IN MS

1.3.1 EXPANDED DISABILITY STATUS SCALE (EDSS)

The EDSS (Kurtzke, 1983) is widely used by neurologists to classify a person's MS-related disability. This scale uses eight functional systems: Pyramidal, Cerebellar, Brainstem, Bladder and bowel, Sensory, Visual, Cerebral and Other. The neurologist grades the function of each system from 0 (Normal) to 6 (Severely impaired). The combination of grades allows the calculation of an EDSS score (minimum 0 'normal neurologic exam all functional systems grade 0' to a maximum of 10 'death due to MS'). The twenty-point scale gives detailed information about a person's level of ability e.g. EDSS 5.5 = Ambulatory without aid or rest for about 100 metres; disability severe enough to preclude full daily activities. EDSS scores 1.0 – 4.5 refer to people who are ambulatory, 5.0 – 9.5 reflect gradually declining mobility, with those who have an EDSS of 7.0 or higher being dependent on a wheelchair for mobility Kurtzke (1983).

1.3.2 PATIENT DETERMINED DISEASE STEPS (PDDS)

Following the widespread use of the EDSS which is determined by a neurologist, the PDDS (Hohol et al., 1999) was developed as a patient-reported outcome measure of MS-related disability. The scale is based on walking distance and independence. People are asked to indicate their own disease severity from 0 (mild symptoms not limiting activity) to 8 (confined to bed, unable to sit in a wheelchair for more than one hour). A PDDS of 6 indicates wheelchair use for distances greater than 25 feet, with those reporting PDDS of 7 having a wheelchair or scooter as their main mode of transport. PDDS and EDSS scores are strongly linked across all levels of disability from mild to severe (Learmonth et al., 2013d).

1.4 PHYSICAL SYMPTOMS OF MS

1.4.1 MUSCLE WEAKNESS/ATAXIA

Muscle weakness, both due to the primary disease and due to deconditioning, affects many people with MS. Quadriceps and hamstring strength are reduced compared to healthy controls, even in those who can walk independently. However, the differences are more marked in those who need assistance from walking aids (Thoumie et al., 2005). Lower limb muscle weakness is closely linked to MS-related disability. Those with milder disability (EDSS 0-3.5) have been found to have significantly better strength in five lower limb muscle groups compared to those with moderate disability (EDSS 4.0 – 5.5) (Mañago et al., 2018). A high proportion of people with MS are also affected by a lack of muscular co-ordination of the limbs, or ataxia, resulting from involvement of the cerebellum, (Mills et al., 2007). The combination of weakness and poor co-ordination has a significant impact on function including balance and gait, which will be described in further detail below. In the clinical setting, muscle strength can be measured using dynamometry (Mañago et al., 2018, Güner et al., 2015), which quantifies the generation of force. Other measures of gait and balance also show the impact of muscular problems on functional activities.

1.4.2 POOR BALANCE

Poor balance is a common problem in MS due to spasticity and muscle weakness from the condition itself and also due to physical deconditioning. Problems with balance often lead to people becoming less active, which in turn causes further deconditioning and a greater risk of falls. Results from a systematic review showed that more than half of participants had experienced a fall during a six to twelve month period (Gunn et al., 2013). As well as impaired balance, risk factors leading to a greater likelihood of falling were: a diagnosis of progressive MS, deterioration in EDSS, use of a mobility aid, spasticity, and continence problems. Functional balance can be assessed using the Berg Balance Scale (Krupp et al., 1989). This involves fourteen everyday tasks designed to challenge balance e.g. standing with feet together or turning 360^{0}. Participants attempt each task and are scored on a scale from (0) unable to (4), fully independent. This measure is suitable for a broad spectrum of disability and has been used widely in studies into exercise and MS.

1.4.3 LIMITED MOBILITY

The effects of MS on muscle strength, co-ordination, and balance all have an impact on a person's walking mobility. Assessment of mobility independence forms a key part of both EDSS and self-reported PDDS disability measures. A range of measures are used to determine walking impairment. Objective measures include the timed 25ft walk (Motl et al., 2017a), timed up and go (TUG)

(Podsiadlo and Richardson, 1991), which also incorporates sit-to stand and turning. The MS walking scale (MSWS-12) (Motl and Snook, 2008, Goldman et al., 2017) was designed to specifically assess subjective walking ability. Both the TUG and the MSWS-12 were shown to be valid and reliable for use in MS (Learmonth et al., 2013b). Speed to complete the TUG was found to be significantly different according to neurological disability in groups of mildly, moderately, and severely affected patients (Kalron et al., 2017).

1.4.4 REDUCED AEROBIC FITNESS

Aerobic fitness has also been shown to be lower in people with MS (Langeskov-Christensen et al., 2015) than in the general population, particularly older people with MS and those who have higher levels of disability (Motl et al., 2006, Langeskov-Christensen et al., 2015). Submaximal and maximal exercise tests have been used to determine aerobic fitness in MS. For example, Motl et al., (2017d) used an incremental maximal exercise test on a cycle ergometer in patients with a median PDDS of 4.0. It has been found that even in those with mild MS disability, the energy cost of walking was higher than for healthy participants (Franceschini et al., 2010). The increased likelihood of lowered exercise tolerance, and higher risk of adverse events during exercise in those with chronic conditions, has popularised the use of submaximal tests which are adapted to the needs of specific test populations (Gappmaier, 2012). For people with MS, a cycle ergometer protocol has been developed to assess aerobic fitness. The test begins at a low workload (20 watts) gradually increasing in intensity in three to four stages over a period of fifteen to eighteen minutes (Gappmaier, 2012). The test is terminated when a participant reaches either voluntary exhaustion or 85% of age-adjusted maximum heart rate. Heart rate is measured at each stage, allowing maximum heart rate to be estimated. Rated perceived exertion (RPE) is also taken at each stage of the test. In previous work in submaximal cycle ergometer tests in MS, RPE scores were found to be associated with both workload and oxygen consumption during the exercise (Cleland et al., 2016).

1.4.5 SPASTICITY

MS frequently leads to muscle spasticity (Compston and Coles, 2008). This is described as: ‘‘disordered sensori-motor control, resulting from an upper motor neurone lesion, presenting as intermittent or sustained involuntary activation of muscles” (Pandyan et al., 2005). Patients may experience muscle stiffness, or painful spasms which commonly affect the flexor muscles of the upper limbs and the extensor muscles of the lower limbs (Tintoré, 2015). Spasticity is complex to manage and can also be worsened by other disease-related factors. For example, constipation, urinary tract or other infection, poorly fitted mobility aids, pressure ulcers, posture and pain can all exacerbate spasticity (NICE, 2014b). Spasticity has an impact on everyday function including sit to stand, gait, and balance.

1.4.6 ALTERED SENSATION AND PAIN

Sensory systems are often affected in MS. Compston and Coles (2008) report two sensory disturbances which are common in MS: Lhermitte’s symptom, causing an electrical sensation down the limbs or spine when the neck is flexed, and Uhthoff phenomenon, a short-lived worsening of symptoms on increasing the core body temperature. Both of these things can affect a person’s level of activity, for example a person may be reluctant to take part in exercise if the resultant increase in body temperature causes symptom exacerbation. An unpleasant feeling of tightness around the chest or abdomen, termed the ‘MS hug’ has also been described when demyelinating lesions are present in the thoracic spinal cord (Ford, 2020). Neuropathic pain, occurring as a direct consequence of a lesion or disease affecting the somatosensory system (Treede et al., 2008) can also be present in MS. This type of pain can be described as burning, piercing, or can imply that pain is felt when non-painful stimuli are applied (Solaro et al., 2013). People with MS are more likely to develop trigeminal neuralgia, a recurrent electric shock like pain in the distribution of the trigeminal nerve (Di Stefano et al., 2019). Studies into the prevalence of pain in MS vary from 29 – 91% (Solaro et al., 2013), this can also include musculoskeletal pain from altered posture or position. Pain has wide-ranging effects on quality of life, participation in activity at work and leisure, as well as affecting mood (Solaro et al., 2013). The assessment of the severity and nature of a person’s pain are an important part of understanding the individual’s experience of MS. Visual analogue pain scales are commonly used in MS to quantify pain (Castro-Sanchez et al., 2012).

1.4.7 VISUAL PROBLEMS

Visual symptoms often present early in MS (Brownlee and Miller, 2014). These can include diplopia, a reduction in visual acuity and/or scotoma (Compston and Coles, 2008). An inflammatory lesion in the optic nerve leads to optic neuritis, causing impaired vision, and pain often on eye movement (Thompson et al., 2018b). Nystagmus can lead to oscillopsia, abnormal eye movements and/or a sensation of movement of the surroundings (Thompson et al., 2018b).

1.4.8 BLADDER/BOWEL DYSFUNCTION

Bladder problems are common in MS and can include urinary incontinence, frequency, urgency and nocturia. The bowel can also be affected leading to faecal incontinence, or constipation. Bladder and bowel problems can be particularly disabling, affecting daily activities and social interactions for people with MS. A study with over 9000 respondents, found 66% to be affected by both bladder and bowel symptoms, and 91% affected by at least one out of bladder, bowel and sexual symptoms (Wang et al., 2018). Level of disability was associated with the perceived impact of these symptoms. Bladder and bowel dysfunction can affect social activities and participation in exercise.

1.5 PSYCHOLOGICAL SYMPTOMS OF MS

1.5.1 FATIGUE

The Multiple Sclerosis Council for Clinical Practice Guidelines (1998) defined fatigue as "a subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activities". Fatigue from MS is chronic, described as fatigue present for any amount of time on 50% of days for more than six weeks, and which limits functional activities or quality of life. The nature of fatigue was also described by the Council as either primary (occurring as part of the MS disease process) or secondary to other factors, such as medication for chronic illness, depression or sleep difficulties. Around 70% of people with MS report themselves to have fatigue (Rooney et al., 2019b, Hadjimichael et al., 2008). The prevalence of fatigue is higher in those with progressive MS than other forms of MS, and the severity of fatigue is also greater in this group (Rooney et al., 2019b).

Several questionnaires have been developed to measure fatigue in MS. Fatigue can be quantified using the Fatigue Severity Scale (FSS) (Krupp et al., 1989). This questionnaire assesses how easily people are fatigued and the level to which fatigue affects physical functioning, work and family life. Another commonly used scale is the Modified Fatigue Impact Scale (MFIS) which measures the physical, cognitive and psychosocial impact of fatigue (Fisk et al., 1994). Physically, fatigue can affect coordination, mobility and aerobic fitness (Rooney et al., 2019b). Indeed higher MFIS physical scores were found to correlate inversely with performance on the six-minute walk test (Goldman et al., 2008) in a group of people with MS. Lack of exercise can also compound the problem of physical deconditioning, making people more fatigued (Krupp et al., 2010). Memory, concentration, and decision-making are also impacted by fatigue, which can cause impaired performance of cognitive tasks (Krupp et al., 2010). The psychosocial effects of fatigue can lead to a lack of motivation for social activities, and therefore can have a significant impact on the person's daily life. The psychosocial impact of fatigue has been found to be greater in those with progressive MS than other forms of MS (Rooney et al., 2019b).

1.5.2 IMPAIRED MEMORY AND COGNITION

Deficits in attention, reasoning and executive functioning are reported in MS (Compston and Coles, 2008). Common cognitive impairments in a study of 291 people with MS were deficits in visual memory, speed of processing, verbal and working memory (Chiaravalloti and De Luca, 2008). As mentioned above, cognitive ability can also be impacted by fatigue (Krupp et al., 2010), meaning that those affected by fatigue may also have these difficulties. All of these problems can affect a person's ability to work, take part in social activities and family life.

1.5.3 DEPRESSION

Depression can be defined as a mood disorder causing symptoms which may include sad, anxious, or "empty" mood, feelings of hopelessness, guilt, worthlessness, or helplessness or loss of interest or pleasure in activities (National Institute of Mental Health 2018) . Depression is more common in people with MS than in the general population. Recent review studies find an estimated prevalence of between 24% (Marrie et al., 2015b) and 31% (Boeschoten et al., 2017). These differences are likely to be due to how depression is assessed, with both studies reporting a lower prevalence in diagnosis by a clinician than when depression is determined using a questionnaire. For example, when depression was assessed by questionnaire, the prevalence of depression was as high as 46% (Marrie et al., 2012). The link between MS-related disability and depression is not clear, however imaging studies have shown an association between structural changes within the brain and symptoms of depression (Feinstein, 2011). Depression has also been shown to be associated with other MS symptoms, including fatigue (Rooney et al., 2019b, Brown et al., 2009). The latter two-year longitudinal study also showed that higher levels of depression were also predictive of anxiety, recreational drug use, smoking, and lack of exercise (Brown et al., 2009). Higher depression in MS is also associated with thoughts of suicide, with 29% reporting suicidal ideation in one study (Turner et al., 2006). The Hospital Anxiety and Depression Scale (HADS) is a commonly used questionnaire measuring depression in MS (Marrie et al., 2015b). A particular strength of using HADS is that its assessment of depression is independent of fatigue, unlike some measures of depression, and has therefore been recommended for use in MS (Bol et al., 2009).

1.5.4 ANXIETY

Generalised anxiety is usually defined as showing excessive anxiety or worry, most days for at least six months. Symptoms can include feeling restless, "wound-up", or on-edge, with difficulty concentrating, irritability and muscle tension (National Institute of Mental Health 2018). Anxiety is more common in MS than in the general population, affecting 16.5% in a questionnaire-based study (Marrie et al., 2012). Anxiety in MS is most commonly assessed using the HADS Score (Marrie et al., 2015b).

1.5.5 QUALITY OF LIFE

As a long-term condition affecting people from their twenties onwards (Ford 2020), people with MS often live with changing symptoms for many years. Quality of life, or the self-reported effect of a condition on an individual's physical and mental wellbeing (Berrigan et al., 2016), is known to be negatively impacted in people with MS (Marrie et al., 2012). A recent review synthesised the literature relating to risk factors for poor quality of life, as well as factors that benefit quality of life in MS. High EDSS score, reflecting greater disability was a main cause of poorer quality of life, as well as progressive onset MS, recent relapse and unemployment (Gil-González et al., 2020). Other factors associated with lower quality of life were fatigue, depression, anxiety and physical comorbidities (Berrigan et al., 2016). Correlations were found between higher self-esteem, self-efficacy, resilience and social support with better scores on quality of life measures (Gil-González et al., 2020). Interventions to improve mental health in MS have been shown to have a positive impact on quality of life (Gil-González et al., 2020).

1.5.6 MEASUREMENT OF THE OVERALL IMPACT OF SYMPTOMS

The Multiple Sclerosis Impact Scale (MSIS) (Hobart et al., 2001) is a questionnaire designed to measure the perceived impact of a participant's MS. Twenty items refer to physical aspects (e.g. 'Being clumsy', 'Spasms in your limbs') and nine to the psychological impact (e.g. 'Problems concentrating'). Scoring allows a total percentage for physical impact and psychological impact of MS to be calculated. This commonly used questionnaire has been shown to be a valid and reliable measure of both physical and psychological constructs in MS (Riazi et al., 2002). The physical scale of the measure has been shown to be responsive to deterioration in EDSS, with scores increasing with the worsening of disability (McGuigan and Hutchinson 2004). Greater fatigue has also been found to be associated with greater physical and psychological impact of MS (Veldhuijzen van Zanten et al., 2021).

1.6 CO-MORBIDITIES AND LIFE EXPECTANCY

Physical and mental health co-morbidities are common in people with MS. Depression and anxiety are both more prevalent in people with MS than the general population, discussed in the previous section. A study of 8983 participants showed common self-reported physical comorbidities to be hypercholesterolaemia, (affecting 37%) and hypertension (affecting 30%) (Marrie et al., 2012). A further review showed levels of ischaemic heart disease, congestive heart failure, ischemic stroke, and peripheral vascular disease to be higher in people with MS than in the general population (Marrie et al., 2015a). The authors suggest that this could be due to the higher prevalence of smoking, and higher body mass index in MS. In addition, further self-report data has shown migraine to affect 17%, and chronic obstructive pulmonary disease to affect 10% of people with MS (Berrigan et al., 2016), with 57% reporting one or more comorbidities. Low levels of physical activity are also common in MS (Casey et al., 2018a), which could perhaps contribute. Results from a self-report study of 8755 people with MS showed that being less physically active was associated with a higher disability level, greater fatigue, and depression, hand or bladder dysfunction, or spasticity (Reider et al., 2017). High levels of sedentary behaviour have also been observed in people with MS, and sitting time has been related with higher blood pressure in MS (Hubbard et al., 2018). These comorbidities and increasing disability over years with a diagnosis of MS have contributed to the reduction of life expectancy of approximately seven years in MS compared to the general population (Lunde et al., 2017, Palmer et al., 2020). Diagnosis of MS at a younger age was found to lead to a relatively shorter life expectancy than diagnosis at an older age (Lunde et al., 2017). People diagnosed with relapsing remitting MS were also observed to live a median of 17 years longer than those with primary progressive MS (Lunde et al., 2017).

1.7 IMPACT ON EMPLOYMENT

Peak age for onset of MS symptoms is between 20-40 years (Ford, 2020), therefore people live with the condition for a large part of their working lives. The nature and unpredictability of MS symptoms affects peoples' ability to sustain employment and this appears to increase with age. Employment rates in people with MS were reported at 51.2% in those aged 38 years (Lorefice et al., 2018), 41.1-43.8% in those aged 48 years (Julian et al., 2008), and 40.8% in a group with a mean age of 52 years (Li et al., 2015). In addition to older age, other factors associated with either lower likelihood of being employed, or loss of employment were a lower educational level, worsening of symptoms over the previous six-month period, reduced mobility and strength, poorer hand function, fatigue, and cognitive impairment (Li et al., 2015, Julian et al., 2008). Lorefice et al (2018) also reported that higher disability levels were linked to lower self-reported ability to work, manage the home, and take part in social and leisure activities.

1.8 MEDICAL TREATMENT

There is no cure for MS, but there are a wide range of medical treatments which can be used to manage MS symptoms, particularly for relapsing remitting disease which is the most common. Treatment is divided into three types of medications, which are described below.

1.8.1 DISEASE MODIFYING THERAPIES

Disease modifying therapies (DMTs) are most suitable for patients with relapsing remitting disease and have been approved for use since the 1990's (Thompson et al., 2018a). At time of writing there are fifteen DMTs licensed for use in the UK. The mechanism of action varies between different DMTs. Many of them modulate the immune response by acting on T or B cells to reduce CNS inflammation. This reduces the number and severity of relapses (Thompson et al., 2018a). For those who are diagnosed with progressive forms of MS, the majority of DMTs are not proven to be effective. However one DMT, Ocrelizumab is the first to be licensed for the treatment of primary progressive MS (Thompson et al., 2018b) and Siponimod has recently been licensed for the treatment of secondary progressive MS (NICE, 2020b).

1.8.2 MEDICATION FOR THE TREATMENT OF RELAPSES

When patients demonstrate symptoms of a relapse, the most common pharmacological management involves a course of steroid treatment. UK NICE guidelines (NICE, 2014b) recommend 0.5g daily for five days of the oral steroid methylprednisolone. If administered early (i.e., as soon as possible and within 14 days of symptom onset following NICE guidelines) this reduces the inflammatory process and accelerates recovery from a relapse.

1.8.3 MEDICATION FOR THE TREATMENT OF SPECIFIC SYMPTOMS

As the symptoms of MS vary greatly from person to person there are a wide range of medications available to treat them. Some of the commonly used drugs are detailed in Table 1.1, with details of drug type and effects (British National Formulary 2021).

Table 1.1: Overview of symptomatic medication used in MS

Symptom	Medication	Classification and Effects
Spasticity	*Systemic medication:* Gabapentin or Baclofen (NICE, 2014). *Localised treatments:* Intrathecal baclofen, botulinum toxin (Doshi and Chataway 2016).	Muscle relaxant, relief of chronic severe spasticity. Intrathecal baclofen can be given if there is no response to oral dose
Ataxia/tremor	Propranolol, clonazepam, levetiracetam, isoniazid (with pyridoxine), carbamazepine, ondansetron (Thompson et al., 2018a, Doshi and Chataway, 2016)	Beta-blocker, relief of tremor
Bladder dysfunction	*Frequency/urgency:* oxybutynin, solifenacin, tolterodine, mirabegron *Nocturia:* desmopressin/DDAVP spray (Thompson et al., 2018a, Doshi and Chataway, 2016).	Antimuscarinic, for relief of bladder spasms
Bowel dysfunction	*Constipation:* Fibre/fluid, bulking agents, lactulose, suppositories, transanal irrigation *Faecal incontinence:* Codeine, loperamide (Doshi and Chataway 2016).	Lactulose, osmotic stimulant laxative for constipation relief. Loperamide, anti propulsive for relief of diarrhoea
Depression	Citalopram duloxetine (Doshi and Chataway, 2016)	Citalopram – Selective serotonin reuptake inhibitor (anti-depressant)
	Amitriptyline for emotional lability (Thompson et al., 2018a).	Tricyclic antidepressant
Oscillopsia	Gabapentin (Thompson et al., 2018b)	Anti-epileptic (unlicensed use for oscillopsia)
Fatigue	Amantadine	Dopamine receptor agonist (unlicensed use for MS fatigue)
	Modafinil (NICE, 2014b, Thompson et al., 2018b)	Modafinil - centrally acting sympathomimetic for relief of fatigue
Neuropathic pain	Amitriptyline, pregabalin, gabapentin, lamotrigine (Thompson et al., 2018a, Doshi and Chataway, 2016)	For relief of peripheral neuropathic pain.

1.9 NON-MEDICAL THERAPIES TO MANAGE SYMPTOMS

1.9.1 MULTIDISCIPLINARY INPUT

A co-ordinated multi-disciplinary approach is advocated in the management of MS (NICE, 2014b). This ensures that individuals are supported by a range of professionals with expertise tailored to their specific needs. Problems experienced are likely to be different from person to person. For example, as a non-medical treatment for depression, people can be referred to a neuropsychology service or for cognitive behavioural therapy (Thompson et al., 2018a). Fatigue management is offered by occupational therapy (Thompson et al., 2018a), with physiotherapy exercise programmes also effective for improving fatigue (Pilutti et al., 2013b). Working jointly, occupational therapists and physiotherapists can develop rehabilitation programmes to improve balance, gait, and daily function within the home or workplace.

1.9.2 COMPLEMENTARY AND ALTERNATIVE MEDICINES

Complementary and alternative medicine has also been used in the management of MS symptoms. Use of cannabis was self-reported by 26% of 5000 people surveyed in a recent study. Among this group it was perceived to be effective in treating spasticity by 76%, pain by 63%, and an overactive bladder by 20% (Cofield et al., 2017). Sativex, a cannabis-derived oral spray has been developed for the treatment of spasticity for people with MS. Since 2019 NICE has supported a four-week trial of the use of Sativex in UK patients for whom other medications listed in Table 1.1 are not effective (NICE, 2019). A systematic review of 38 studies into complementary therapies in MS also found some evidence that cannabis treatment resulted in improvements in incontinence, pain and spasticity compared to control treatments (Claflin et al., 2018). However the methodology of this study did not adhere to the Cochrane criteria for a systematic review, due to a lack of allocation concealment and intention to treat analysis, therefore results should be interpreted with caution (Cochrane Collaboration 2011). Another review of eleven systematic reviews focusing on the use of cannabinoids alone to treat MS symptoms (Nielsen et al., 2018) found some evidence to support their use for the treatment of pain and spasticity, but also reports of adverse effects e.g. dizziness, nausea and dry mouth in eight of the studies. From the evidence into the use of cannabinoids, it appears that they may be of benefit to some patients with MS who experience spasticity and pain. However, their use needs to be carefully assessed and monitored. A range of other alternative therapies have also been used to relieve the symptoms of MS. Acupressure, amphetamine salts, reflexology, and relaxation were effective in single studies, but their effects were not replicated, suggesting evidence was not conclusive to support their use (Claflin et al., 2018). Exercise was also included as a modality in this study of complementary treatments for MS, with promising outcomes across a range of exercise programmes. The evidence for exercise as a way to manage MS symptoms will be explored further below.

1.10 PHYSICAL ACTIVITY AND EXERCISE IN MULTIPLE SCLEROSIS

Physical activity and exercise in people with MS are main topics of this thesis. The previous section has briefly introduced physical activity as a way to manage common MS symptoms. In this section, more information will be provided about both physical activity and exercise in MS. This will include levels of physical activity and previous research into physical activity and exercise interventions in management of symptoms of MS.

1.10.1 PHYSICAL ACTIVITY

Physical activity is accumulated as part of a wide range of daily tasks and is defined as “any bodily movement produced by skeletal muscles that results in energy expenditure” (Caspersen, Powell et al. 1985). Physical activity can be classed as light intensity, including standing housework such as ironing, or gentle walking, moderate intensity including vacuuming or sweeping, and brisk walking or vigorous intensity to include heavy gardening, running and taking part in sports. Due to the nature of their symptoms, people with MS may find physical activity more challenging than healthy people. The majority of people with MS are less physically active than the general population (Klaren et al., 2013, Kinnett-Hopkins et al., 2017a). However, associations have been found between symptoms of MS and levels of physical activity. For example higher levels of physical activity are associated with lower levels of physical fatigue (Blikman et al., 2018) and depressed mood (Kratz et al., 2019). Taking part in more physical activity has also been associated with better walking mobility measured by the Timed Up and Go and six-minute walk test (Weikert et al., 2012) and greater aerobic fitness (Motl et al., 2017c). A recent expert paper has recommended that people with MS be assessed early after diagnosis by a health or exercise professional to establish an individualised programme of physical activity (Kalb et al., 2020). Two systematic reviews of interventions designed to increase physical activity in people with MS have shown increases in both subjective and objective assessments of physical activity (Casey et al., 2018b, Sangelaji et al., 2016). Studies aiming to increase physical activity in people with MS over a six-month period have resulted in significant improvements in measures of fatigue, symptoms of depression (Motl and Sandroff, 2020b) and anxiety (Pilutti et al., 2013a), as well as self-reported walking ability (Motl et al., 2017b). The latter study also reported a reduction in EDSS, reflecting lower overall disability status in the intervention group compared to controls.

1.10.2 EXERCISE

Exercise is a subset of physical activity: “a planned, structured and repetitive form of physical activity carried out to improve one or more elements of physical fitness” (Caspersen et al., 1985). The American College of Sports Medicine guidelines (ACSM 2014), state that exercise can include activities to improve health-related fitness, e.g., lifting weights for strength, or skill-related fitness, e.g., co-ordination of the upper and lower limbs for a swimming stroke. In healthy adults the benefits of regular exercise are known to include better cardiovascular health with a lower risk of heart disease as well as type II diabetes (ACSM 2018). Exercise is also known to improve bone health, and physical function with mental health benefits to quality of life and depression (ACSM 2018). People with MS are reported to be less physically fit than healthy people (Langeskov-Christensen et al., 2015), and frequently report functional difficulties such as poor balance leading to increased risk of falls (Gunn et al., 2013) as well as mental health problems (Marrie et al., 2015b). The effects of exercise on the symptoms of people with MS have therefore been investigated in a large number of recent studies. There is now substantial evidence for the benefits of exercise in people with MS. These benefits include improvements in muscle strength, speed and endurance of walking, improvements in quality of life (Latimer-Cheung et al., 2013b), cardiovascular fitness (Platta et al., 2016a), MS-related fatigue (Pilutti et al., 2013b) and improvements in depressive symptoms (Herring et al., 2017). The mechanisms by which exercise affects MS symptoms are debated in the literature. There have been suggestions that physical activity and exercise can modify the process of disease by normalising the effect of inflammatory cytokines and adipokines in the central nervous system of people with MS (Kjølhede et al., 2016). However, a review study found evidence for the effects of both physical activity and exercise on the cytokine and adipokine profiles of people with MS to be lacking (Negaresh et al., 2018). This may be due to the measurement of inflammatory markers in the blood serum rather than in the central nervous system where they are present in MS. It has also been proposed that exercise can improve symptoms by inducing neuroplasticity in people with MS (Motl and Sandroff 2020). One review found seven studies demonstrating exercise-related changes in magnetic resonance imaging or other imaging of the CNS which were associated with exercise-related functional improvements in people with MS (Sandroff et al., 2020). However, the overall results of the review were inconclusive as to the role of neuroplasticity due to the lack of blinding, and large variation in type and frequency of exercise. Most included studies were pilot or feasibility studies and thus underpowered to detect change (Sandroff et al., 2020). Despite the lack of clarity into how exercise affects MS symptoms, there is ample evidence to support various exercise programmes being beneficial for people with MS. This section will first discuss the evidence for exercise safety for people with MS, followed by a report of the benefits of a range of different types of exercise in MS, followed by support needed to encourage people with MS to take up exercise and sustain exercise behaviour.

Safety of Exercise in MS

In the past, there has been concern about the risk of exercise exacerbating the symptoms of MS. As a result of this, people newly-diagnosed with MS were advised to avoid physical activity and exercise (Halabchi et al., 2017). However, more recent research has shown the potential for exercise as a safe way to improve function and manage the symptoms of MS without aggravating disease activity. A systematic review investigated the incidence of MS relapse across 26 studies, including aerobic, resistance exercise, combined exercise, and yoga. In participants with mild to moderate MS, the risk of relapse was no greater for the exercisers compared to controls (Pilutti et al., 2014). The National Institute of Clinical Excellence (NICE) provide guidance on the delivery of high-quality healthcare, developed collaboratively with patients, carers, and a range of health professionals. Their statement on physical activity in MS (NICE, 2016) also endorses the safety of exercise, stating that exercise does not have harmful effects and is likely to be beneficial. Both increasing physical activity and aerobic exercise training have been linked to health benefits in MS, such as a reduced risk of cardiovascular events (Langeskov-Christensen et al., 2015) and improvements in fatigue, depression, anxiety, and pain (Pilutti et al., 2013a). In recent years, researchers have investigated various forms of exercise for people with MS. The majority of studies have targeted a combination of strength, balance and aerobic fitness or mobility. The section below will therefore give an overview of studies into a range of exercise modalities for people with MS.

1.11 EFFECTS OF EXERCISE ON MS SYMPTOMS

1.11.1 STRENGTH TRAINING

Muscle strength training is defined as a systematic way of a muscle or muscle group lifting, lowering or controlling heavy loads (resistance) for a relatively low number of repetitions over a short period of time with a resulting adaptation being an increase in force-production or muscle strength (ACSM 2014). 'Strength' and 'resistance' training can be used interchangeably to describe this type of exercise and both of these terms will be used in this section. Common methods of strength training include the use of manual resistance from a therapist, free or mechanical weights, and elastic resistance bands (Kisner and Colby 2012). A number of studies have used strength training programmes for people with MS across a range of disability levels. A systematic review of resistance training programmes reported consistent improvement in the strength of hamstrings, quadriceps and plantarflexors across sixteen studies, in participants with EDSS below 6.5. The programmes varied in duration and intensity, but exercises were usually carried out twice weekly. This review also found improvements in fatigue (Kjølhede et al., 2012). A meta-analysis showed that in participants with mean EDSS 2.0 – 4.0, progressive resistance training improved strength, power, and explosive strength in the lower limbs (Jørgensen et al., 2017). A review study advocated resistance training to be supervised for people with MS, at least initially, for safety and to ensure the person is comfortable with the programme (Dalgas et al., 2008). Class based programmes, commonly eight to twelve weeks duration, have utilised strengthening exercises at different intensities. For example, one programme consisted of upper and lower limb exercises using a resistance band (Hayes et al., 2017b). Participants with mean EDSS 3.3 started with one set of 10-15 repetitions of each exercise with sets, repetitions and resistance gradually increasing (Hayes et al., 2017b). Grazioli et al. (2019) similarly used a 50% of one repetition maximum intensity for twice weekly strengthening exercises in their programme (participants mean EDSS 4.7). Other class-based exercise programmes have used low-intensity strengthening exercises carried out three times each week, with Sangelaji et al. (2014) using 10-15 minutes of spring resistance exercises (EDSS 4.0) and Moghadasi et al. (2020) using total body suspension resistance (EDSS 2.4).

Effects of the class-based strengthening programmes included improvements in mobility, such as better six-minute walk performance (Sangelaji et al., 2014, Coote et al., 2014, Grazioli et al., 2019), Timed Up and Go (Grazioli et al., 2019, Moghadasi et al., 2020), self-reported walking (Coote et al., 2014)(Coote et al., 2014), and Berg balance scale scores (Sangelaji et al., 2014). Grazioli et al. (2019) also saw a small reduction in EDSS following their intervention, showing the potential for exercise of this type to reduce overall MS disease severity. Other reported improvements included physical and mental health related quality of life and fatigue (Sangelaji et al., 2014, Grazioli et al., 2019). Apart from Moghadasi et al (2020), the other class-based studies also included aerobic training in their programme, however like the strengthening exercise the intensity of the aerobic component varied considerably. Aerobic training took the form of walking at 100 steps per minute, increasing in duration over the ten weeks, , ten minutes on a static bike at 65% of maximum heart rate (Grazioli et al., 2019), and exercise on a static bike and treadmill gradually increasing from 10 minutes on each at 40% of maximum heart rate to 20 minutes at 70% of maximum heart rate (Sangelaji et al., 2014). These combined programmes were well tolerated by people with MS, with adherence to the exercise reported to be over 70% by Coote et al. (2014).

Twice weekly strengthening exercises have also formed part of home based studies, two of these took place over six months for people with PDDS of up to 4.0 (Tallner et al., 2016), and mean 4.4 (Donkers et al., 2020). A third study lasted twelve weeks and included people with EDSS of up to 6.0 (Paul et al 2014). All three of these studies began with face-to-face assessments of participants to facilitate prescription of exercises based on their ability, with the ongoing delivery of their exercise programmes via the internet. These home based exercise programmes resulted in improvements in Timed Up and go, muscle strength, physical activity, anxiety and physical and psychological impact measured by the MSIS-29 questionnaire (Tallner et al., 2016, Donkers et al., 2020, Paul et al., 2014b). It is worth noting that these studies also included other exercise components, such as balance (Donkers et al., 2020, Paul et al., 2014b) and cardiovascular exercise (Tallner et al., 2016). These home-based strengthening programmes reported average adherence of 1.2 to 1.7 sessions per week, showing that this method of exercising was well tolerated across disability levels.

SUMMARY OF RESEARCH INTO STRENGTH TRAINING

Strengthening exercises appear to be an exercise modality which can achieve positive results, particularly for balance and gait and after a relatively short duration, the majority of these studies took place over 8-12 weeks. Strengthening exercise programmes have been applied to EDSS scores up to 6.0 and are therefore applicable across a range of abilities. The exercises can be performed in sitting or standing and adapted to the needs of the individual with strength and functional gait and balance measures shown to improve.   Usually the strengthening exercise programme is combined with an aerobic activity, making it difficult to attribute the outcomes to the specific strengthening exercises. The home-based studies have shown that there is much potential for this type of exercise to be delivered and supported remotely. Additionally, there is good adherence to exercise programmes which can lead to increased physical activity and strength for participants. Based on the literature, a recent expert consensus paper offers strength training recommendations for people at all levels of MS disability. For those with mild disability two or three weekly sessions of strength training is suggested with five to ten exercises, one to three sets of 8-12 repetitions, although intensity is not specified (Kalb et al 2020). For those with higher disability levels the use of bodyweight and functional multi-joint movements is suggested. However published guidelines on exercise for people with MS (Latimer-Cheung et al., 2013a)are for use by those with mild to moderate disability and do not cater for those with greater impairments. As with all exercise programmes prescription should be based on detailed assessment of the individual's strength and function.

1.11.2 BALANCE TRAINING

Balance (also called postural control, postural stability or equilibrium) can be defined as 'the ability to align body segments against gravity to maintain or move the body (centre of mass) within the available base of support without falling' (Shumway-Cook and Woollacott, 2017). Balance exercises are therefore done to create a challenge through bodily movement and maintain this equilibrium during changing postures (Shumway-Cook and Woollacott, 2017). As a frequently mentioned problem for people with MS, many exercise programmes have incorporated activities to improve balance either as part of a multi-faceted exercise intervention or as the main focus of the programme. A review of eleven exercise studies investigating effects on balance outcomes found the main interventions used in the studies comprised aerobic and resistance training with some specific balance exercises (Paltamaa et al., 2012). The review found that compared with no treatment, exercise programmes which included resistance and aerobic training as well as balance exercises had a non-significant effect on balance. Another systematic review of balance interventions in people with MS has reported that for longer term effectiveness in reducing falls, an optimal dose of approximately two hours balance exercises per week is recommended (Gunn et al., 2015). A number of balance-related exercise interventions have been investigated which adhere to these guidelines. Two studies used one to one 30 minute core stability exercise sessions for people with MS done weekly over twelve weeks (Fox et al., 2016) or twice weekly over eight weeks (Freeman et al., 2010), with participants also required to complete fifteen minutes of the exercises daily at home. For both studies, the exercises used were done in lying, four-point kneeling or standing, tailored to the needs of the individual with EDSS from 4.0 – 6.5. Fox et al. (2016) used a Pilates approach, focusing on activation of the deep abdominal muscles, for their balance component. The same core stability exercises were used by Forsberg et al. (2016) as part of a class-based programme consisting of two hours per week over seven weeks for people with EDSS approximately 4.0 – 6.0. The programme, which aimed to improve mechanisms used for balance during functional tasks (trunk stability, dual tasking and sensory strategies) also included dual task exercises, e.g. walking combined with a cognitive task, and exercises challenging different sensory strategies, e.g. standing with eyes closed (Forsberg et al., 2016). Two other class-based studies used a similar range of Pilates exercises twice per week for 60 minutes over eight weeks in groups with lower disability, Küçük et al. (2016) with mean EDSS of 3.0 and Guclu-Gunduz et al. (2014) with median EDSS of 2.0. Adherence to these programmes was reported to be over 80% (Guclu-Gunduz et al., 2014, Fox et al., 2016).

Improved Berg balance scores were reported by Forsberg et al. (2016), Küçük et al. (2014) and Guclu-Gunduz et al. (2014) compared to control groups with the latter two studies also reporting better Timed Up and Go. Control group protocols varied from home breathing and extremity exercises (Guclu-Gunduz et al., 2014), to “traditional “ strength balance and coordination exercises (Küçük et al., 2016), and no exercise (Forsberg et al., 2016). Forsberg and colleagues also reported improved functional gait assessment and self-reported walking ability. Interestingly, one study did not include any exercises in a standing position, yet the results also showed better timed walk performance (Küçük et al., 2016). In contrast, the study by Fox et al. (2016) did not find the Pilates intervention to significantly improve gait speed, compared to a control group who attended relaxation classes. There was a small non-significant increase in gait speed for both the Pilates group, and a slightly larger one for a comparator group who completed ‘standardised exercises’ (similar to the Pilates exercises but without specific focus on deep abdominal activation), with only the standardised exercise group sustaining the improvement at a four week follow-up. The participants in the study by Fox et al. (2016) were more disabled, having an EDSS of 4.0 – 6.5, so it is possible that standardised exercises may have been more functionally relevant to them. Indeed, attendance at the standardised exercise sessions was higher at 84% compared to 66% for the Pilates sessions. These results show that both Pilates-based and more traditional balance programmes are well tolerated by people with MS, and can show improvements in measures of balance, mobility and gait speed.

Other programmes for balance have utilised virtual reality gaming systems, which can enhance the rehabilitation environment and add interest for participants. Kalron et al., (2016) used a Computer Assisted Rehabilitation Environment (CAREN) for a programme of 30 minutes of one to one standing balance activities, twice a week over six weeks, in patients with a mean EDSS of 4.1. Participants with similar EDSS (mean 4.0) took part in two other studies, a comparison of one to one sessions progressing in difficulty using the Nintendo Wii and Balance Trainer (Yazgan et al., 2020) and a pilot study using balance-based games on the Nintendo Wii carried out at home (Thomas et al., 2017). The CAREN programme resulted in significant improvements in the balance measures : Berg Balance Scale, Four Square Step Test, and Functional Reach Test for both the virtual reality and a control group who did ten minutes of stretching, and twenty minutes of supervised standing balance activities (Kalron et al., 2016). The CAREN group also reported a reduced fear of falling, however the study was just six weeks in duration, with no follow up measurement of the longer-term impact. Additionally, the programme had no home exercise component, meaning it would be impossible to sustain unsupervised or beyond the period of the study. Both programmes using the Nintendo Wii resulted in improvements in the Timed Up and Go. Yazgan et al. (2020) also reported improved six-minute walk distance, and Fatigue Severity Scale compared to controls, with the Nintendo Wii group improving significantly more in Berg Balance Scale and MS Quality of Life measure than the Balance Trainer group after eight weeks (Yazgan et al., 2020). Thomas et al. (2017) reported an average of two 27-minute sessions per week using the Wii for each participant, over the six months with qualitative data showing the Wii was viewed very positively. As a commercially available device this suggests there is potential for this to be used by people with MS independently and over a longer period. These programmes using gaming systems appear popular, and can result in balance and gait improvements, however consideration should be given to ensuring that suitable home exercise to support the programme is also given when they are of relatively short duration.

The above programmes have been focused purely on balance exercises. These exercises have also been combined with flexibility and strengthening in MS. Tarakci et al. (2013) carried out a group-based programme three times per week over 12 weeks for participants with EDSS scores of 4.0. The programme included core stability, balance, and coordination exercises and functional activities, as well as flexibility, range of movement, and strengthening exercises. Participants were instructed to work up to an RPE score of 13/20. They found significant improvements in 10-metre walk test and Berg Balance Score, as well as Fatigue Severity Scale, and spasticity for calf, hamstring and hip flexors in the intervention group compared to controls.

SUMMARY OF RESEARCH INTO BALANCE TRAINING

Balance training programmes vary widely in the time spent on the balance activities, with studies reporting one to two hours per week on average, but with study duration from six weeks to six months. Although balance and functional improvements are seen after six weeks it is not clear whether these are sustained without continued exercise. It is also notable that the majority of the participants in the balance-focused studies had some impairment to their walking (EDSS 3.0 or above) showing that this type of programme can be applied to those who are more disabled. Pilates and core stability exercises appear easy to transfer into the home environment and require some training but little equipment. In contrast, virtual reality gaming systems may only be available at a centre, and need trained therapist support both when delivered to groups or one on one, which has resource implications for the long-term involvement of people with MS. Options such as the Nintendo Wii, which is commercially available, and designed to be used independently at home may provide an alternative to people who prefer to exercise in this way.

1.11.3 AEROBIC TRAINING

Aerobic exercise training has been defined as exercise which uses large muscle groups and challenges the cardiorespiratory system. This can take different forms, such as cycling or swimming, or everyday activities such as walking or stair climbing (Kisner and Colby 2012). Systematic review evidence has shown that people with MS have a significantly lower average $VO_{2\ max}$ compared to healthy controls (Langeskov-Christensen et al., 2015). However the same authors also showed that improvements in cardio-respiratory fitness are possible in people with MS through aerobic training, and that these improvements in are likely to be associated with other health benefits such as reduced risk of cardiovascular events (Langeskov-Christensen et al., 2015). A review of seventeen studies, fifteen of which had an aerobic component either as the sole exercise modality or combined with other modalities, found aerobic training to be associated with a significant reduction in fatigue (Pilutti et al., 2013b). The intensity of aerobic exercise in these studies was not specified, however reviews have identified that most aerobic exercise programmes in MS are carried out at 60% of VO_2 $_{max}$ or 60 - 80% of maximum heart rate, corresponding to more moderate intensity (Dalgas et al., 2008, Latimer-Cheung et al., 2013b).

Carter et al. (2014) used moderate intensity aerobic fitness training as the main exercise modality in their study for participants with a mean EDSS of 3.8. Exercise (community-based walking, use of a stepper, treadmill, bike or arm crank) was performed over an increasing duration per session and with fewer rests, at 50-69% of maximal heart rate or Borg RPE 12-14 out of 20. The aerobic training was combined with individualised balance and strengthening exercise in a programme which included weekly centre-based exercise with additional self-directed home exercise. Other studies have evaluated more intense aerobic exercise programmes in MS. Heine et al. (2017) investigated a programme of thirty-minute exercise sessions consisting of six aerobic interval cycles of three minutes at 40% of peak power, one minute at 60% and one minute at 80%. The programme was carried out three times per week over sixteen weeks in people with an EDSS of 3.0 or lower. Another centre-based study used one-minute intervals at 90-110% of maximum tolerated power, each followed by three minutes of low speed recovery in participants with EDSS of 2.0. Five sets of intervals were followed by a five-minute overall recovery. The twelve-week aerobic programme done twice weekly was combined with weekly progressive lower limb resistance training (Zaenker et al., 2018). A similar 40-week aerobic and strength training programme was carried out by Guillamo et al. (2018) for people with EDSS < 3.0. High intensity intervals were performed at RPE 15-18, alongside strength training with a resistance band, balance and flexibility exercises with a fit ball. Guillamo et al. (2018) aimed to compare the outcomes of a combined home and face to face exercise group with a group doing home exercise only. Their home exercise group attended four supervised exercise sessions at the start of the study, continuing the interval training and other exercises independently at home. Overall adherence to the programmes was good. Over 75% adherence to both home and centre-based exercise sessions was reported in the two studies where home and centre-based exercise was combined (Carter et al 2014, Guillamo et al 2018). Heine et al, (2017) also reported 74% adherence in the first eight weeks decreasing to 66% during weeks 8-16.

Cardiorespiratory fitness was reported to improve from these programmes (Guillamó et al., 2018, Zaenker et al., 2018, Heine et al., 2017). Guillamo et al. (2018) also found better 30-second sit to stand performance. Notably the improvements in both VO_2 peak and 30-second sit to stand were only present in their combined exercise group, not in the home exercise only group. Fatigue was also found to improve in two of the studies (Heine et al., 2017, Carter et al., 2014). Improved quality of life as well as isometric quadriceps and hamstring strength was reported after 12 weeks of combined training (Zaenker et al., 2018). Carter et al (2014), in the study of lower intensity exercise, did not measure cardiorespiratory fitness, but did report increases in daily device-measured step count and self-reported physical activity, in addition to health-related quality of life after 12 weeks. This suggests that an exercise programme of intensity high enough to achieve aerobic fitness benefits, may be difficult to reproduce at home. Centre-based high intensity programmes, although improving fatigue and functional performance appear to be offered only to those with lower disability (up to EDSS of 3.0) and may not be suitable for those with greater physical impairments.

Aerobic Training - Walking

A subset of aerobic fitness training, exercise programmes for MS frequently involve planned and structured periods of walking. As highlighted previously, the physical problems associated with MS, including muscle weakness, spasticity, and poor balance have an impact on walking. Exercise studies in MS frequently target walking mobility as a primary outcome, as losing the ability to walk independently has a big impact on the individual's everyday function, and significantly increases the need for care. A systematic review has shown that for people with MS across a range of disability levels, exercise programmes mainly consisting of aerobic and resistance training improve both walking speed and endurance (Pearson et al., 2015). However, walking can also be used as the mode of exercise, and walking as an exercise activity may be more suitable for people with higher levels of disability. Sandroff et al. (2017) reported that a multimodal exercise programme (including either treadmill walking or recumbent stepping) led to increased six-minute walk distance for people with substantial mobility disability from their MS. In another study of those with higher disability level (EDSS of 6.0 – 8.0) the use of a bodyweight support treadmill and recumbent stepper for gait training resulted in increases in training workload and speed in both groups (Pilutti et al., 2016). Similarly robot-assisted treadmill training was employed in people with EDSS of 6.0 – 6.5 by Straudi et al. (2020). The treadmill training had similar effects to a control condition of over ground walking, with significant improvements in 25ft walk, walking endurance, Berg Balance Scale scores and quality of life for both groups.

The studies mentioned above have often used assisted walking for people with high levels of disability. However a meta-analysis of nine studies found that the improvements in gait speed over short or long distances from robot assisted gait training were not superior to conventional gait training (usually over ground walking either gym or community-based) in people with a mean EDSS between 5.0 and 6.6 (Sattelmayer et al., 2019). The authors suggested that the maximum speed for some of the treadmills used may have been slower than the self-selected walking pace of participants with lower disability levels, meaning those participants would perform better in conventional gait training programmes. Over ground walking has also been used as the aerobic exercise component in other studies in people with MS. One method involved participants being given a pedometer and advised walking at 100 steps per minute, (moderate intensity exercise for people with MS) beginning at ten minutes twice weekly and increasing by five minutes per week until 30 minutes twice weekly was reached (Hayes et al., 2017b, Learmonth et al., 2017b, Mayo et al., 2020). Two studies with participants of EDSS up to 3.5 reported good compliance with 70-75% of aerobic sessions being completed (Hayes et al., 2017a, Learmonth et al., 2017b). One study reported a mean increase of nine minutes per day of intensive walking in participants with EDSS up to 5.5 (Mayo et al., 2020). There were also improvements in self-reported physical activity (Learmonth et al., 2017b) and in six-minute walk distance which was maintained at six month follow up (Hayes 2017). Walking as an exercise is widely available, can be adapted to be more or less intensive, and can be beneficial to mobility outcomes in MS.

SUMMARY OF RESEARCH INTO AEROBIC TRAINING

A range of aerobic training programmes for people with MS have been studied. The higher intensity programmes appear more suitable for those with lower disability levels. Supervised programmes are more likely to achieve the required higher exercise intensity and these programmes have positive results for aerobic fitness, mobility outcomes, and fatigue. Moderate intensity aerobic exercise for people with MS can take the form of over ground walking, which is easily accessible and well tolerated across a range of disability. Over ground walking can also result in improvements to activity levels and other mobility outcomes. Aerobic training is frequently combined with strengthening, which appears to be well tolerated and increases the benefits of programmes. The recent consensus paper also suggested guidance for aerobic training for people with MS. Two or three sessions per week of ten to thirty minutes at a perceived exertion rate of 11-13 out of 20 was suggested for those with EDSS up to 4.5 (Kalb et al 2020). This is consistent with the guidelines for exercise for people with MS, which are also based on research in those with EDSS of 4.5 and below (Latimer-Cheung et al., 2013a). Kalb et al. (2020) additionally offered a range of example activities, with more challenging recommendations for those already taking part in regular aerobic exercise. These included increasing exercise time to 40 minutes, RPE to 15 out of 20 and including a weekly session of high intensity interval training (Kalb et al 2020). This highlights the need for a range of options within each exercise type to cater to needs across the disease spectrum.

1.11.4 SUMMARY OF FINDINGS FROM EXERCISE STUDIES IN MS

Exercise programmes in MS have included different exercise modalities. Strength programmes in MS can be adapted for the needs of those across a range of MS disability, and muscle strength increases in the quadriceps and hamstrings have been reported after only 8-12 weeks. Strengthening exercise programmes can also improve gait and balance outcomes as well as fatigue. Balance-focused exercises range from Pilates or core exercises requiring no equipment to the use of virtual reality systems, both of which can be applied to those with mobility impairments. Balance programmes appear popular with participants, and lead to improvements in balance outcomes, although little data is available on the longer-term effects of taking part. Aerobic exercise can also take many forms, from low to moderate intensity over ground walking, technology-assisted walking or gym-based intervals of higher intensity training. The higher intensity aerobic programmes appear to be more suitable for those without mobility problems, and show benefits for fitness, fatigue, and functional outcomes. More moderate intensity aerobic exercise, including walking can also achieve benefits for health outcomes and is well tolerated by people with MS.

Exercise programmes combining two or more of these three elements appear to be commonly used for people with MS. The programmes vary in their nature, but offer variety of activities over the days of the week and appear to be popular with people with MS, showing good adherence. They can also be adapted to the needs of people across a range of disability. Like a number of the exercise programmes discussed above, the MS specific guidelines recommend combined exercise, specifically two 30-minute sessions per week of moderate to vigorous physical exercise and twice weekly strength training for people with mild to moderate MS (Latimer-Cheung et al., 2013a). The guidelines resulted from a systematic review of 54 studies, which concluded that aerobic fitness and strength in people with MS could be improved by moderate intensity exercise carried out twice a week (Latimer-Cheung et al., 2013a). A feasibility study to test these exercise guidelines in people with EDSS ≤ 2.0 showed increased self-reported physical activity. Given the high compliance with the exercise programme (71%), this suggests that exercising within these parameters is an acceptable level for people with MS with a low disability level (Learmonth et al., 2017b). The review which informed the guidelines included only studies of participants with EDSS of 1.0 – 5.5, meaning all participants were able to walk 100m or more. However due to the variety offered in the different types of exercise programmes mentioned above it may be possible to create and pilot a combined programme which is also suitable for those with greater mobility impairments.

1.11.5 HOME BASED AND CLASS-BASED EXERCISE

A range of exercise programmes delivered both at home and in gyms or therapy departments have been discussed. Home based exercise has significant benefits for people with MS including being able to schedule exercise sessions according to one's disease fluctuations and daily commitments and removing the need to travel to an exercise facility. However, class-based exercise also has advantages, allowing instructor supervision to ensure that exercises are performed safely and that appropriate progression occurs, as well as offering peer support to the class members. A number of studies of exercise interventions in have been entirely home-based and delivered over the internet. Learmonth, Adamson et al. (2017b) performed such an intervention as a pilot study for MS exercise guidelines, and reported 71% compliance with sessions over sixteen weeks. Other studies also used home based exercise with average adherence rates of 1.3 – 1.5 times per week (Paul et al., 2014b, Donkers et al., 2020). The latter study was conducted over six months, with a reported decline in participation in months four to six. Tallner et al. (2016) also delivered their internet exercise intervention over six months and found 80% compliance with strength training in the first half of the study, which dropped to 36% in the second half. Qualitative data showed that these methods were popular with participants, with Paul et al. (2014) reporting that participants found the resources user-friendly and would exercise in this way again. Thomas et al. (2017) also reported that the Nintendo Wii was popular with participants in their home-based study. Two studies which were wholly class based reported adherence rates of 100%, in a virtual reality balance intervention over eight weeks (Yazgan et al., 2020) and a twelve-week combined strengthening and aerobic programme (Grazioli et al., 2019). Adherence of over 80% for 96% of participants was reported in another combined twelve week class (Tarakci et al., 2013).

Class participation with additional home exercise is another method used in some studies. Carter et al. (2014) reported 90% compliance with aerobic and strengthening exercise classes, and 81% with home exercise over three months. Guclu-Gunduz et al. (2014) also reported full adherence to twice weekly home exercise over eight weeks, with just two individuals missing one class-based session. Fox et al. (2016) in their balance programme, reported 84% compliance for standardised exercise classes but only 66% for Pilates classes. For the home components, participation was more similar at 80% for the Pilates group and 78% for standardised exercise. Other research has compared the use of the same exercise with home and class based groups. Williams et al. (2021) compared a home-based and class-based group taking part in an eight-week progressive gait, balance and functional strength programme. Compliance with the classes was 83%, but only 45% in the home group. Despite this, there was no difference in the gait speed and balance outcomes between the two groups, however participants were only asked to carry out two sessions per week. Guillamo et al.

(2018) compared a combined class and home group with a home group taking part in high intensity aerobic exercise over 40 weeks. In contrast to Williams and colleagues (2021), six exercise sessions per week were included in their programme. In the first 20 weeks exercise compliance in the combined group was 78%, and 50% in the home group, with lower compliance in the second half (63% and 45%, respectively). In this study there was a difference in outcomes with the group having both class and home sessions making significant improvements in VO_2 peak and 30-second sit to stand compared to those doing only home exercise (Guillamó et al., 2018). Platta et al., (2016) in a review of the effects of exercise on fitness in MS, found that supervised exercise programmes resulted in greater improvements in cardiorespiratory fitness than unsupervised programmes, although the difference was not significant. These authors advocate the development of more effective unsupervised exercise programmes for people with MS. Indeed from the research above it appears that there is much potential for home-based exercise of varying types for people with MS, although some issues with adherence, particularly after the first 10-12 weeks, suggesting consideration should be given to methods of supporting people to participate over the longer term.

1.12 PARTICIPATION IN PHYSICAL ACTIVITY AND EXERCISE IN MS

Despite the large amount of evidence to support physical activity and exercise as a methods to improve a range of MS symptoms, low levels of physical activity mean the majority of people with MS are not physically active enough to achieve health benefits (Klaren et al., 2013, Motl et al., 2015b, Cavanaugh et al., 2011). Research has shown that physical activity levels in people with MS are lower than those in the general population, but appear to be similar to those living with other chronic neurological conditions (Kinnett-Hopkins et al., 2017a). In addition to this, when people with MS take up exercise, dropout rates of 23% from class-based programmes (Garrett et al., 2012) and up to 53% from home programmes (Conroy et al., 2018) have been reported. There is a need to identify the reasons for these low levels of physical activity from the perspective of people with MS, to understand how they can best be supported to achieve the health benefits of physical activity.

1.12.1 BARRIERS TO EXERCISE IN MS

Research into the perceptions of exercise in people with MS has shown that there is awareness of the importance of exercise for health and wellbeing (Backus, 2016, Crank et al., 2017). Despite this recognition of the benefits of regular exercise, a number of barriers have been cited by people with MS. One example is symptoms preventing exercise (Kayes et al., 2011). People have also reported a worsening of symptoms following exercise, such as fatigue, which then reduced their motivation for further exercise (Plow et al., 2009, van der Linden et al., 2014). Also linked to possible effects on symptoms, a systematic review reported fear and apprehension of exercise to be a commonly identified barrier (Learmonth and Motl 2016). People with MS also mentioned experiences such as falls during exercise which impacted negatively on their feelings about participating (Kayes et al., 2011). As well as symptom-related barriers, people with MS have reported feelings of self-consciousness during exercise. This was evident particularly when exercising with others in a leisure setting, rather than health-related setting and could lead to them avoiding taking part in exercise (van der Linden et al., 2014, Learmonth et al., 2013c). On a practical level, access problems to leisure facilities have also been reported as a barrier to exercise (Borkoles et al., 2008, Plow et al., 2009). Other environmental barriers have also been highlighted including people being without transport to access exercise facilities which may be some distance away, or a lack of groups specific to their MS disease stage, particularly for those with greater disability (Riemann-Lorenz et al., 2019).

People with MS have also reported barriers related to the professionals who provide the exercise. For example, people with MS reported a lack of confidence in the staff of a leisure facility to help them set up an exercise programme suitable for their personal needs (Borkoles et al., 2008, Crank et al., 2017). In addition, a dissatisfaction with the amount and timing of information from health professionals about exercise has also been highlighted by people with MS (Learmonth et al., 2017a) or even a lack of routinely offered lifestyle and exercise advice after diagnosis with MS (Crank et al., 2017). As the health and exercise professionals are responsible not only for referring to exercise schemes, but also for providing the exercise programmes, and monitoring participation and progress, it is also important to be aware of their views. Qualitative research with health professionals confirmed some of the barriers mentioned by people with MS. A lack of knowledge about MS from some neurologists and physiotherapists leading to them giving at times conflicting exercise advice was identified in one study (Learmonth and Motl, 2016). From overcoming symptoms and individual worries, to the practicalities of providing accessible exercise environments and professional support, there are complex barriers to be addressed in the setting up of exercise programmes for people with MS.

1.12.2 FACILITATORS TO EXERCISE IN MS

As mentioned above, people with MS have reported to be aware of the benefits of exercise to help their symptoms (Borkoles et al., 2008). People with MS reported exercise taking place in an environment suitable for those with disabilities as a facilitator to their participation (Learmonth and Motl, 2016). People with MS felt that their exercise instructors should be educated about MS-related problems, and have skills to adapt exercises for their needs (Learmonth and Motl, 2016, Smith et al., 2013). Good communication, and the value of in-person meetings with the instructors to support exercise participation was also a factor identified by both health professionals and people with MS (Learmonth et al., 2020). People with MS stated the importance of exercise programmes incorporating choice to suit the needs of people with different abilities Learmonth et al. (2013c). The provision of choices of exercise activities to facilitate long-term participation have been identified in qualitative studies of the views of health professionals (Riemann-Lorenz et al., 2019, Backus, 2016). Exercise for MS can be delivered in different ways, including through generic leisure facilities and through healthcare providers. A novel 'Blue Prescription' physiotherapy approach which tailored exercise activities towards very specific individualised goals was praised as being motivating and enabling (Smith et al., 2013). Condition-specific exercise classes or groups providing opportunities for peer support were viewed as helpful by people with MS (van der Linden et al., 2014). Health professionals highlighted a need for options to include group and individual as well as web-based exercise (Riemann-Lorenz et al., 2019). People with MS also identified a need for specific instructions and ideas for strategies to maintain an exercise routine (Smith et al., 2013). The perspective of both people with MS and health professionals about barriers and facilitators is important in the planning of any exercise intervention to assist in meeting the needs of those delivering and participating in the programme. Based on the findings of previous research it would be useful to understand the views of these two groups in the context of the current proposed exercise programme. The studies in chapters 3 and 4 therefore focus on the perspectives of people with MS, and professionals working with people with MS on the proposed exercise programme and supporting strategies.

1.13 SUPPORTING PEOPLE WITH MS TO EXERCISE

Given the barriers to exercise for people with MS reported above, and their low levels of physical activity, taking up a regular exercise programme involve a significant change in behaviour for many people with MS. Therefore, there is a need to give appropriate behaviour change support alongside the exercise intervention. It is also important to recognise that participants need different support at all stages. Encouraging somebody to take up a programme is a different process from helping adherence to the programme and continuation with the behaviour post-intervention. A consensus paper based on expert opinion and research evidence highlighted the potential for behavioural interventions to increase and sustain physical activity in people with MS and to result in benefits to both symptoms and overall function (Motl et al., 2015a). The authors suggested that finding the most suitable behavioural interventions to promote physical activity change is one of the top ten research questions related to physical activity and MS. The next section will explore what is known about the effects of different behavioural interventions which have been utilised in MS.

1.13.1 THE HEALTH ACTION PROCESS APPROACH

The Health Action Process Approach (HAPA) (Schwarzer et al., 2011) is a model of behaviour change which has been proposed for people with chronic illness. The model suggests that behaviour change takes place in a series of phases, the first of which is a motivation phase where intentions or goals are formed. The authors describe three main factors which influence the formation of these intentions. Firstly, the importance of 'positive outcome expectancies' such as the health benefits of the desired action have been highlighted (Schwarzer et al., 2008). The second factor is a person's belief of being capable to carry out the action or 'action self-efficacy', and thirdly risk perception, where a person will consider their personal risk as a result of not taking action. When intentions to act have been formed, people enter the volitional phase, which involves translating their intentions into actions, and importantly maintaining those actions (Schwarzer et al., 2011). During the volitional phase there is a need for 'maintenance self-efficacy', a person's positive belief about dealing with problems while the behaviour is being maintained. Schwarzer et al. (2011) have described two types of planning which can support this phase. Action planning relates to the 'when, where, and how' of a new behaviour, while coping planning involves the anticipation of possible barriers to the new behaviour and problem solving to ensure that these barriers do not prevent the actions from being maintained. When the person is a regular 'actor', having taken on the new behaviour, the self-efficacy required may be 'coping self-efficacy'. This is defined as employing more effort, different strategies or perseverance when the behaviour is more difficult to continue than anticipated (Schwarzer, 2008). 'Recovery self-efficacy', experiencing failure and subsequently recovering from setbacks may also be required to maintain the behaviour (Schwarzer, 2008). Throughout the phases of the behaviour change, behaviour can be influenced by barriers and resources. Barriers are any outside factors which impede the performance of the behaviour, and may be more complex in clinical populations than in others (Schwarzer et al., 2011). Resources assist the behaviour change, and can include social support, which may negatively impact the adoption of a new behaviour if not present (Schwarzer et al., 2011).

Studies have utilised aspects of this model to promote behaviour change in MS, and particularly in programmes of physical activity rather than specifically exercise. Review studies into behaviour change techniques to promote physical activity in people with MS, found that of 23 studies, most used multiple behaviour change techniques, with some reporting up to thirteen (Casey et al., 2018b, Sangelaji et al., 2016). Exercise based studies have also reported the use of behaviour change techniques reflecting the principles of HAPA such as goal setting and action planning (Learmonth et al., 2017b, Thomas et al., 2017). Even though exercise and physical activity are different behaviours, techniques used to change physical activity behaviour are often similar to those used to support uptake and maintenance of exercise. Including the evidence for physical activity programmes will therefore give a more detailed overview. This section will aim to provide a summary of behaviour change support in line with HAPA which has been used as part of exercise and physical activity interventions for people with MS.

1.13.2 SETTING GOALS OR INTENTIONS

Developing intentions is part of the motivational phase of the HAPA, which relates to goal setting. Review studies into behaviour change techniques to promote physical activity in people with MS, found that two of the most commonly used methods were "goal-setting *behaviour*" (e.g., short-term goals related to performing the activity) and "goal-setting *outcome*" (e.g., longer-term goals of functional improvement) Casey et al. (2018b), (Sangelaji et al., 2016). Outcome related goal setting links to the concept of risk perception within the motivational phase of the HAPA. This refers to a person's view of the potential negative consequences of not performing a behaviour (Schwarzer, 2008). Goal setting has therefore been employed as part of behaviour change support for a number of programmes for people with MS. An example of a behaviour-related goal could be to carry out five leg muscle strengthening exercises twice a week, whilst an outcome-related goal would be to take the dog for a walk for thirty minutes without resting. Exercise studies report that participants were encouraged to set goals as part of pre-programme assessments, either individually (Thomas et al., 2017, Carter et al., 2014, Donkers et al., 2020, Paul et al., 2014b) or in a group (Coote et al., 2014). Goal setting was also done remotely via video chat during another exercise intervention delivered by DVD (Learmonth et al., 2017b) and as part of an internet-delivered physical activity intervention (Motl et al., 2017b). The use of goals can make the anticipated outcomes of an intervention clear and supports self-efficacy. For this reason, goals have also been used for many years as part of physiotherapy and other rehabilitation therapies for people with MS. There is a need for support in goal setting, to ensure the goals are SMART (specific, measureable, achievable, realistic and timed) (Khan et al 2008). However, one study found that people with MS and healthcare professionals disagreed on two thirds of goals set for each individual for an inpatient stay. The people with MS were found to be more optimistic than the health professionals about the likelihood of goals being achieved (Bloom et al., 2006). In an effort to support better collaboration, the more structured method of goal attainment scaling has been used in MS. This involves goals, and specific levels of attainment, being agreed jointly by the patient and therapist, which relate to performance of daily activities (such as exercise) in the short term or longer-term functional outcomes (such as independent transfers) (Khan et al., 2008). In a population of patients with low back pain, a patient-led goal setting exercise intervention was shown to be more effective in improving pain, disability, quality of life and self-efficacy than a control condition of standardised exercise advice only (Gardner et al., 2019).

In people with MS, supported goal setting has also been shown to increase self-reported physical activity compared to control conditions (Thomas et al., 2017, Carter et al., 2014, Motl et al., 2017b, Learmonth et al., 2017b). A recent review also highlighted that goal-setting improved after some interventions using behaviour change techniques to increase physical activity in people with MS (Casey et al., 2017). The review also found a positive association between goal setting and subjective physical activity in MS. A similar method of collaborative goal attainment scaling as part of physiotherapy treatment was used in one study in inpatient rehabilitation in MS, (Khan et al., 2008). Results showed that 82% of 203 goals were achieved at the predicted level or above, by people with MS across a range of disability, however this study did not employ a control condition. Other reported health benefits from interventions incorporating goal setting were improvements in fatigue, depression and anxiety (Motl et al., 2017b, Pilutti et al., 2013a, Coote et al., 2017). The former two studies used a waiting list control group. The control group in the latter study received generic health education sessions. Overall results showed improved aerobic capacity, cognitive processing, and physical impact of MS after three months (Coote et al., 2017). At six month follow up, the goal setting group showed sustained improvements in a range of physical and mental health outcome measures, which were not present in controls (Coote et al., 2017). Two of these studies also measured goal setting using a questionnaire, and found significant improvements in both goal setting and planning ability in their participants following the intervention (Coote et al., 2017, Motl et al., 2011). All of these results support joint goal setting between people with MS and those supporting them to change their activity behaviour, which should include education on how to set appropriate and meaningful goals. This can improve MS-related symptoms as well as future ability to set and stick to goals.

1.13.3 TRANSLATING INTENTION INTO ACTION

The HAPA recognises that the setting of goals or intentions does not automatically result in a person acting on those intentions. At this stage a person may be motivated to change, but may not have the skills to turn intention into action. Planning becomes a key aspect here, bridging the gap between intention and behaviour (Schwarzer et al., 2011). A cross-sectional study into the use of the HAPA in exercise promotion for people with MS found that self-reported use of action planning had a strong direct effect on engagement in physical activity (Chiu et al., 2011). However, in relation to physical activity interventions in MS, two reviews have shown that action planning was only used in three studies, two of which were by the same author (Casey et al., 2018b, Sangelaji et al., 2016). Action planning has been used more in recent years since those reviews were published. One exercise-based study mentioned above used action planning in addition to goal setting (Thomas et al., 2017). Participants created a general action plan stating the days of the week they intended to exercise, leading to a mean participation of twice weekly over six months (Thomas et al., 2017).

Another, very specific type of action planning, i*f-then* planning, has been used in MS and other clinical populations to support adherence to mobility-related goals, such as being able to walk independently down the path to the front gate (Kersten et al., 2015a). *If-then* plans are also termed implementation intentions, and encourage participants to specify where, when and how a goal would be put into practice (Orbell and Sheeran, 2000). For example, in the case of exercise: "*If* – I am up by 7am, *then* – I will do my exercises in the dining room while I watch the morning news". These if-then plans mean that a person commits to responding to a certain situation in a specific way (Gollwitzer 1999), so that *if* the first situation occurs *then* the desired action will be performed*. If-then* implementation intentions were used in a study following joint replacement surgery. Goals were set at the start of each week, specifying e.g. when and where the action of a walk would be taken. Compared with controls the implementation intention group returned to functional activities more quickly (Orbell and Sheeran, 2000), suggesting the wider application of this method in rehabilitation. A systematic review showed that *if-then* plans were also successfully used to support better medication adherence in epilepsy and stroke (Kersten et al., 2015b). They have also been used in MS. A small scale 12-week study of MS and stroke patients found that a brief intervention, (a total of up to 90 minutes including one face to face and one telephone session) enabled the use of *if-then* plans to support a home exercise programme for achieving mobility goals. There were improvements in self-reported health status in the *if-then* planning group compared to controls. Qualitative findings also showed that participants valued this approach to aid in exercise planning and fine tuning, while therapists found *if-then* planning a straightforward method to provide positive support to their patients (Kersten et al., 2015b).

An additional way of supporting action plans in behaviour change interventions is the development of a 'facilitative plan'. Participants are asked to select three helpful factors which would encourage them to stick to their personal action plans and to think of ways to bring about these factors. For example, a person may choose having time to exercise as a helpful factor, and getting up earlier as a way to facilitate this. Facilitative plans were used in an intervention to increase daily walking in healthy participants resulting in an average increase from 20 to 32 minutes per day (Darker et al., 2010). A physiotherapy-led intervention to increase physical activity in people with MS has also used facilitative plans (Ryan et al., 2017). Participants took part in a series of one-to-one sessions each including goal setting and a focused discussion of personal barriers and facilitators to becoming more physically active. In comparison to a control group receiving usual care participants increased self-reported walking, as well as improving levels of pain, fatigue and self-efficacy (Ryan et al., 2020).

1.13.4 COPING PLANNING

The HAPA recognises the importance of establishing a routine incorporating the behaviour change and preventing a return to previous behaviour (relapse prevention). The use of the specific methods of action planning outlined above allow for a clear structure to be set for the desired behaviour. However, HAPA recognises that there will be times when other factors affect these plans. Schwarzer et al. (2011) describe coping planning as anticipating barriers which may affect the performance of the intended action, and devising other ways to ensure the action is still done, despite these problems. A person is already equipped with a back-up plan rather than having to come up with such a plan when the difficulty arises. Therefore, the coping plan works together with the action plan to maintain the behaviour (Sniehotta et al., 2006).

Coping planning requires participants to respond to questions such as ‘what barriers or issues may prevent you from sticking to your exercise plans?’ ‘What strategies can you use to overcome them?’ Sniehotta et al. (2006) advocate encouraging people to write very precise and personally relevant coping plans. The successful use of combined action plans and coping plans has been observed in cardiac rehabilitation. On discharge from hospital participants in one study were divided into a control group, a group who created only exercise action plans, and a combined planning group, who additionally created exercise coping plans in a brief 30-minute intervention. Participants had no other contact with the researchers post-discharge and were followed up two months later. At this point the combined planning group did more exercise than either the controls or those who used action planning alone (Sniehotta et al., 2006). To date coping planning has been used little in MS. Two recent systematic reviews of behaviour change techniques used to increase physical activity in people with MS, identified that although the majority used similar methods such as “barrier identification/problem solving”, across 23 studies, none specifically identified coping planning (Sangelaji et al., 2016, Casey et al., 2018b). Schuler et al. (2019) advocated using coping planning with people with MS when adopting a new exercise behaviour, giving the example of fatigue being a likely frequent barrier. The coping plan would encourage people to remind themselves of feeling good after a previous walk if their fatigue threatened to stop them from taking part in an activity (Schuler et al., 2019).

1.13.5 DEVELOPING SELF-EFFICACY AND MONITORING BEHAVIOUR

The HAPA emphasises the importance of an individual's perceived self-efficacy at all stages of the process of behaviour change (Schwarzer et al., 2011). Self-efficacy can be developed through experience of mastering a behaviour, observing others, verbal persuasion or physiological feedback (Bandura, 1997). One method of encouraging self-efficacy, which has been used in physical activity behaviour change for people with MS is self-monitoring, which was employed in the majority of studies in two systematic reviews (Casey et al., 2018b, Sangelaji et al., 2016). Self-monitoring can be done throughout a behaviour change intervention, to encourage reflection on progress and to reinforce the maintenance of exercise behaviours. Exercise diaries or logbooks, either paper or online, which are periodically reviewed by the researchers have been used in a number of studies (Donkers et al., 2020, Paul et al., 2014b, Thomas et al., 2017, Learmonth et al., 2017b, Hayes et al., 2017a). All of these interventions reported a mean adherence of 1.3-2 sessions per week over the study period. Some studies have additionally included education for participants as part of an intervention, about the principles of self-monitoring and developing self-efficacy. This was done face to face in a group setting (Hayes et al., 2017b), via interactive video (Motl et al., 2017b), or video chat (Learmonth et al., 2017b). The latter study was the only one to measure self-efficacy using a questionnaire, however this did not change as a result of the intervention (Learmonth et al., 2017b). However, a recent review of mainly cross-sectional studies found that both objectively and subjectively assessed physical activity were positively associated with self-efficacy (Casey et al., 2017) suggesting the value of physical activity and exercise interventions also using techniques to support self-efficacy.

1.13.6 SUMMARY OF BEHAVIOUR CHANGE APPROACHES

An important theme of the studies which appear to have used behaviour change successfully in MS is the recognition of the need for support at all stages of the process. Review findings showed that studies mostly used multiple behaviour change techniques. Behaviour change support can be provided face to face or by telephone, internet, or messaging platforms. Goal setting is frequently used both in rehabilitation and exercise or physical activity interventions. Following the setting of suitable goals improvements have been seen in physical activity and other health outcomes including fatigue, as well as increased goal setting ability. The use of specific action plans, to make the new behaviour a part of peoples' routine is also increasing in studies with people with MS. Coping planning is similar to the problem solving and identifying barriers previously used in MS, and has helped to improve exercise outcomes in other populations. Coping plans may be particularly relevant in MS due to fluctuations in symptoms, and therefore clear instruction on their use has potential to support people with MS to anticipate and deal with problems which may arise when carrying out the new exercise behaviour. Both action planning and coping planning assist in developing self-efficacy in the new behaviour. Self-monitoring also supports self-efficacy, with successful approaches to this including the use of an exercise diary to record and reflect on progress. Diaries can be paper or online based, and having an interactive element with the researchers also appears to support maintenance of the behaviour.

1.14 SEDENTARY BEHAVIOUR IN MS

1.14.1 WHAT IS SEDENTARY BEHAVIOUR?

As well as their levels of physical activity, recent attention in the research has turned to sedentary behaviour in people with MS. Rather than a lack of physical activity, or a definition of not meeting physical activity guidelines, sedentary behaviour is a distinct concept. Sedentary behaviour is defined as any waking behaviour with an energy expenditure ≤1.5 metabolic equivalents (METs), while in a sitting, reclining or lying posture (Tremblay et al., 2017).

1.14.2 HEALTH IMPLICATIONS OF SEDENTARY BEHAVIOUR

In the general population studies have investigated associations between sedentary behaviour and a range of health outcomes. Results of this research suggests greater levels of sedentary behaviour are associated with an increased incidence of type II diabetes, cardiovascular disease and cancer, as well as greater risk of all-cause mortality, cardiovascular disease mortality and cancer-related mortality (Biswas et al., 2015, Katzmarzyk et al., 2019). Even though physical activity and sedentary behaviour are independently associated with health, the health implications of sedentary behaviour were more evident in people who were physically inactive (Katzmarzyk et al., 2019). Sedentary behaviour has also been shown to be negatively associated with mental health such as depression (Zhai et al., 2014) and anxiety (Allen et al., 2019), as well as other health outcomes including quality of life, cognitive function, frailty and reduced physical function (Saunders et al., 2020).

1.14.3 RESEARCH INTO SEDENTARY BEHAVIOUR IN MS

Recent studies have begun to investigate sedentary behaviour in MS. Due to the nature of their condition, there is an assumption that a sedentary lifestyle is common among people with MS. There is now more research emerging about sedentary behaviour in MS, and a need for deeper understanding of sedentary behaviour in MS (Motl and Sandroff, 2020a). Levels of sedentary behaviour in people with MS have been found to be higher than the general population at 9-10.5 hours per day (Jeng et al., 2019, Motl et al., 2017d). Those with higher levels of disability are also known to have greater levels of sedentary behaviour (Cavanaugh et al., 2011, Hubbard et al., 2015, Sasaki et al., 2018b). The emerging research has shown some associations with sedentary behaviour and health in people with MS. Greater levels of sedentary behaviour have been found to be associated with higher blood pressure in people with MS and these associations were independent of body mass index (Hubbard et al., 2018). A recent self-report study has also shown that progressive-onset MS and greater severity of symptoms such as cognitive impairment and fatigue are associated with higher levels of sitting time in MS (Marck et al., 2020). Therefore, knowing more about sedentary behaviour in people with MS may offer a target for intervention to improve health.

1.14.4 MEASUREMENT OF SEDENTARY BEHAVIOUR

To understand more about the associations between sedentary behaviour and health outcomes in MS, methods of assessing sedentary behaviour need to be evaluated. Sedentary behaviour can be measured objectively using accelerometer devices. These are small non-invasive devices which can be used to measure sedentary behaviour. Sedentary behaviour can also be measured subjectively using a range of questionnaires which detail specific sedentary activities. These measures rely on self-report, but provide more depth of information about the types of sedentary activities. These have been validated for use with different general and clinical adult populations. There is some evidence supporting the use of one, the Marshall Sitting Questionnaire in people with MS. However only a correlation with a small effect size between the questionnaire and accelerometer data was found (Sasaki et al., 2018c). One of the top ten research questions relating to physical activity and MS highlighted the limited knowledge about either amount or distribution of sedentary behaviour in this population (Motl et al., 2015a). The need to validate both subjective and objective measures of sedentary behaviour for people with MS and to understand more about the pattern of how sedentary behaviour is accumulated throughout the day has also been identified (Veldhuijzen van Zanten et al., 2016a). It would be useful to start with the assessment of the most suitable self-report questionnaires which represent a quick and easy way to capture peoples’ daily activities. For this reason the first study of the thesis, reported in chapter 2 focuses on the use of sedentary behaviour questionnaires in MS and participants’ views.

1.15 AIMS OF THE THESIS

This chapter has introduced a number of important topics relating to the background of Multiple Sclerosis (MS) and the use of exercise in its management. This thesis explored a range of aspects related to sedentary behaviour, physical activity and exercise in people with MS using both quantitative and qualitative research methods. Below is a brief overview of the aims of the chapters included in the thesis.

1.15.1 COMPARISON OF SEDENTARY BEHAVIOUR QUESTIONNAIRES IN MS – Chapter 2

Aim: to explore sedentary behaviour in people with MS using existing questionnaires, and investigate the perceptions of people with MS related to these questionnaires. There are a number of self-report questionnaires available for measuring sedentary behaviour, but the suitability of these questionnaires for people with MS has not been assessed. The study presented in Chapter 2 therefore used these questionnaires to explore sedentary behaviour in people with MS. As well as amounts of sedentary behaviour, perceptions of participants about these questionnaires were also investigated. This included opinions related to the clarity of the included questions, ease of completion, as well as the overall accuracy of the questionnaires in reflecting sedentary activity and the appropriateness of the items for the person.

1.15.2 PERSPECTIVES OF PEOPLE WITH MS ON EXERCISE BARRIERS AND FACILITATORS IN RELATION TO A PROPOSED EXERCISE PROGRAMME – Chapter 3

Aim: to increase understanding of the views of people with MS into barriers and facilitators of both beginning and sustaining participation in structured exercise. Participants were asked their views on exercise, based on a proposed exercise programme, and the support to be offered to people when taking up and continuing the programme.

1.15.3 PERSPECTIVES OF HEALTH PROFESSIONALS ON EXERCISE BARRIERS AND FACILITATORS IN RELATION TO A PROPOSED EXERCISE PROGRAMME - Chapter 4

Aim: to examine health professionals' perceptions of facilitators and barriers to exercise programmes for people with MS. Similar to Chapter 3, the discussions were based on a proposed exercise programme and related to the support to be offered to people when taking up and continuing the programme. The decision was made to conduct the studies in Chapters 2 and 3 separately in order to represent a more detailed analysis of the perspectives of each of the two groups.

1.15.4 INTEGRATION OF FINDINGS RELATING TO PERCEPTIONS ON A PROPOSED EXERCISE PROGRAMME OF PEOPLE WITH MS AND HEALTH PROFESSIONALS - Chapter 5

Aim: to integrate the views of both people with MS and healthcare professionals around barriers and facilitators to exercise with the wider literature.

1.15.5 ASSOCIATIONS BETWEEN PHYSICAL ACTIVITY, SEDENTARY BEHAVIOUR, AND MEASURES OF FUNCTION AND WELLBEING IN PEOPLE WITH MS – Chapter 6

Aim: to explore associations between physical activity and sedentary behaviour with a range of outcomes measuring physical and mental health in a group of people with MS. These associations were examined using both subjective and objective outcome measures. All measures were taken as part of the pre-intervention baseline assessment of the intervention reported in the subsequent chapter

1.15.6 A FEASIBILITY STUDY TO INVESTIGATE THE EFFECTS OF AN EXERCISE PROGRAMME ON PHYSICAL ACTIVITY, FUNCTION, AND WELLBEING IN PEOPLE WITH MS – Chapter 7

Aim: to explore the engagement with and the effects of a home exercise programme for people with MS across a range of disability levels. The exercise programme consisted of strengthening, balance, and aerobic exercise (Strong Steady Steps). In addition, a comparison was made between the effectiveness of the programme delivered together with online resources compared to the delivery of the programme without these resources.

1.15.7 GENERAL DISCUSSION – Chapter 8

Aim: to combine the overall findings from the thesis, highlighting key aspects and to make suggestions for future research relating to sedentary behaviour, physical activity and exercise for people with MS.

CHAPTER 2: COMPARISON OF SEDENTARY BEHAVIOUR QUESTIONNAIRES IN MS

ABSTRACT

Background: People with multiple sclerosis (MS) are at risk of developing co-morbidities associated with sedentary behaviour. Despite an increase in studies examining sedentary behaviour in multiple sclerosis, researchers have not yet examined the appropriateness of the content or format of questionnaires assessing sedentary behaviour in multiple sclerosis.

Objective: Evaluate perceptions of sedentary behaviour questionnaires for people with MS.

Methods: Fifteen people with MS completed six validated sedentary behaviour questionnaires: Longitudinal Ageing Study Amsterdam, Marshall Sitting Questionnaire, International Physical Activity Questionnaire, Measure of Older Adults Sedentary Time, Sedentary Behaviour Questionnaire and SIT-Q. Participants' perceptions regarding questionnaire content and format were explored by interviews.

Results: Self-reported sedentary time ranged between a mean of 470 (standard deviation 260) (Measure of Older Adults Sedentary Time) and 782 (322) minutes (Longitudinal Ageing Study Amsterdam) per weekday. Analysis of variance revealed a significant effect of questionnaire on mean sitting time: Longitudinal Ageing Study Amsterdam and SIT-Q yielded higher mean estimates of weekday sitting time than other questionnaires. The questionnaires were viewed as being suitable for use in multiple sclerosis but failed to capture some sedentary activities. Variability of symptoms yielded difficulties in describing a "typical day".

Conclusions: The questionnaires were considered suitable for multiple sclerosis but produced variation in estimated sedentary time. Future work might validate questionnaire data with device-based assessments of sedentary time.

2.1 INTRODUCTION

Multiple sclerosis (MS) is a chronic neurological disease with symptoms such as muscle spasms and weakness, fatigue, poor balance, and visual problems (Compston and Coles, 2008). As there is no cure for MS, treatment is focused on reducing inflammation, relapses, and disease progression, as well as symptom management and restoration of function. There is substantial evidence that physical activity and exercise can improve cardio-respiratory fitness, muscle strength, quality of life, walking mobility and fatigue in MS (Latimer-Cheung et al., 2013b, Snook and Motl, 2009, Pilutti et al., 2013b, Motl, 2014) without increasing the risk for relapse (Pilutti et al., 2014). Yet, the majority of people with MS do not meet public health guidelines for levels of physical activity and are therefore considered physically inactive (Klaren et al., 2013). The search for other health behaviour change opportunities in this population has prompted interest in the other end of the activity spectrum, namely sedentary behaviour (Sasaki et al., 2018a).

Sedentary behaviour is distinct from physical inactivity and is defined as “any waking behaviour characterised by an energy expenditure ≤ 1.5 Metabolic Equivalent Units (METs) while in a sitting, lying or reclining posture” (Tremblay et al., 2017). Evidence from prospective and epidemiological studies in the general adult population suggests greater levels of sedentary behaviour are associated with an increased risk of all-cause, cardiac and cancer-related mortality, as well as incidence of cardiovascular disease, cancer, and type II diabetes (Biswas et al., 2015). Importantly, those associations are independent of physical activity (Thorp et al., 2011). People with MS have a higher risk for cardiovascular comorbidities, such as stroke, myocardial infarction, and heart failure compared to the general population (Marrie et al., 2015a, Jadidi et al., 2013), and sedentary time has been positively associated with blood pressure in MS (Hubbard et al., 2018). Addressing sedentary behaviour could therefore present a suitable approach to improve health outcomes in people with MS

Despite the assumption that people with MS lead a sedentary lifestyle, relatively few studies have examined sedentary behaviour in this population (Veldhuijzen van Zanten et al., 2016a). To date, both objective devices (e.g., accelerometers and activPALs) and questionnaires have been used to quantify levels of sedentary behaviour in MS, estimating daily sedentary time to be between 7.5 hours (Hubbard et al., 2015) and 10.5 hours in this patient population (Motl et al., 2017d). Most consistently, studies have reported that greater levels of sedentary behaviour are associated with more severe disability (Hubbard et al., 2015, Ezeugwu et al., 2015a, Cavanaugh et al., 2011, Sasaki et al., 2018a). In order to explore factors related to sedentary behaviour in people with MS, it is important to evaluate the assessment of sedentary behaviour in this population. Few studies have scrutinized the measurement of self-reported sedentary behaviour using questionnaires in MS.

There are a multitude of self-report questionnaires available for measuring sedentary behaviour. These questionnaires vary in the type and number of questions, as well as the recall period of sedentary activities (Dall et al., 2017). The questionnaires have been developed for specific populations (e.g., older adults), but the appropriateness of these questionnaires and content for people with MS remains to be studied. The current study therefore used existing questionnaires to explore sedentary behaviour in people with MS. Perceptions of participants regarding these questionnaires were also investigated. This included opinions related to ease of completion, the clarity of the questions, as well as the overall accuracy of the questionnaires and appropriateness of the items for the participant.

2.2 METHODS

2.2.1 PARTICIPANTS

Participants were recruited from MS outpatient clinics at the Dudley Group of Hospitals NHS Trust (N = 15). Inclusion criteria were a neurology consultant confirmed diagnosis of MS and proficient in English language. Ethical approval for the study was granted by the East of Scotland Research Ethics Service (Reference number: 15/ES/0194). All participants gave written informed consent for participation in the study.

2.2.2 PROCEDURE

Each of the fifteen participants attended a single visit to Dudley Guest Hospital. At the start of the visit demographic information and clinical characteristics were obtained. Participants then completed six sedentary behaviour questionnaires, which asked them to recall time spent in specific sedentary behaviours and/or total time spent sitting in general or retrospectively according to various time frames (e.g., previous week or previous year). All participants completed the same questionnaire pack with the questionnaires in the order listed below. After completion of the questionnaires, a semi-structured interview related to their perceptions of each questionnaire was conducted. Five participants attended with relatives who assisted them in answering the questionnaires. Relatives were also able to contribute to the interview where appropriate.

2.2.3 QUESTIONNAIRES

Patient Determined Disease Steps (PDDS)(Hohol et al., 1999).

This questionnaire assesses perceived disease severity based on the individual's walking ability. Individuals indicate their disease severity on a scale from 0 (mild symptoms which do not limit activity) to 8 (bedridden and unable to sit in a wheelchair for more than one hour). Scores on the PDDS are strongly associated with scores on the physician determined Expanded Disability Status Scale (Learmonth et al., 2013d).

SEDENTARY BEHAVIOUR QUESTIONNAIRES

The Longitudinal Ageing Study Amsterdam (LASA) (Visser and Koster, 2013).

This questionnaire consists of ten sedentary behaviours (taking a nap on a chair or couch, reading, listening to music, watching television or DVD's, performing a hobby such as knitting or jigsaws, talking with others in person or on the phone, sitting at the computer, performing administrative tasks such as writing a letter or having a meeting, sitting in a car, bus or train, and visiting a church or movie theatre). Participants were asked to state how many hours and minutes on a weekday and weekend day they spent undertaking each behaviour. In adults aged 65-92 years, test-retest reliability calculated using intra-class correlation coefficients (ICC) was good at .71, and weak correlations between self-reported and accelerometer-based assessments of sedentary time were reported (Spearman's ρ = 0.35, p<.05) (Visser and Koster, 2013).

The Marshall Sitting Questionnaire (MSQ) (Marshall et al., 2010).

This questionnaire requires participants to report hours and minutes spent sitting on a weekday and weekend day in five categories: travel, work, television viewing, computer use, and other leisure pursuits. In adults aged 45-63 years, weekday work-based sitting time and home computer use had the highest intra-class correlation coefficients (ICC = .53 – .77), with very poor validity demonstrated for all weekend day items. Reliability tests ranged from low to good (ICC = .24 – .84) across different activities with poorer test-retest reliability for weekend days than weekdays (Marshall et al., 2010).

International Physical Activity Questionnaire - Sedentary question (IPAQ) (Craig et al., 2003).

This forms part of a longer questionnaire about a range of physical activities. Participants are asked to report how much time they spent sitting on average on a weekday and a weekend day in the last seven days. In middle-aged adults, test-retest reliability was good with most of the Spearman's correlation coefficients above .65. Criterion validity measured against accelerometer data was fair to moderate (Spearman's ρ = .26–.39) (Craig et al., 2003).

Measure of Older Adults Sedentary Time (MOST) (Gardiner et al., 2011).

This questionnaire asks participants for the total time in the last week spent on six specific sedentary behaviours (e.g., watching television or DVD's, using the computer/internet, reading, socialising with friends or family, driving or riding in a car or on public transport, doing hobbies such as craft or crosswords) and "other activities" for those not specified. For retired adults (mean age = 73 years), ICC's for test-retest reliability for total sedentary time ranged from low to good (ICC = .23 for other sedentary activities, ICC = .90 for computer use). A moderate association was observed between questionnaire-assessed total sedentary time (the sum of all sedentary behaviours) with accelerometer-assessed sedentary time (Spearman's ρ = .02 – .54) (Gardiner et al., 2011).

Sedentary Behaviour Questionnaire (SBQ) (Rosenberg et al., 2010).

This questionnaire asks about nine different sedentary behaviours: watching television, playing computer/video games, listening to music, talking on the phone, doing paperwork or office work, reading, playing a musical instrument, doing arts and crafts and sitting driving/riding in a car bus or train. Participants indicate the amount of time that they spent undertaking each on a grid with nine options ranging from “none” to “6 hours or more”. Test-retest reliability, in adults (mean age = 20 years), for all items in the questionnaire was better for weekdays (ICC = .64-.9) than weekends (ICC = .51 –.93). Partial correlations (adjusted for potential confounders) between questionnaire-assessed sedentary time with accelerometer-assessed sedentary time were low overall (highest r = .26) in women with no significant correlations in men (Rosenberg et al., 2010).

SIT-Q (Lynch et al., 2014).

This questionnaire consists of 18 multi-part questions. Participants are asked to indicate the usual amount of time that they spent sitting or lying down during work and leisure time over the past twelve months. The sedentary behaviours included work-based sitting, to sitting during mealtimes or while caring for a child or elderly relative. For average past-year total sedentary time in adults, test–retest reliability was fair (ICC = .53). Spearman’s ρ associations between SIT-Q and objectively assessed sedentary behaviour ranged between .22 and .37. The questionnaire generally overestimated sedentary time when compared with objective measures (Wijndaele et al., 2014).

2.2.4 PERCEPTIONS OF THE QUESTIONNAIRES

Perceived ease and accuracy

Table 2.1 shows the questions the participants were asked regarding their perceptions of the ease of completion of the questionnaires and their accuracy.

Table 2.1: Perceived ease and accuracy of questionnaires

1. How clear are the instructions on the questionnaire?^
2. How easy was the questionnaire to complete?^
3. How accurate an account of your sedentary activities does this questionnaire give?^
4. How suitable is this questionnaire for people of your age?^

Note: ^Scored on a scale from 1 (very clear, easy, accurate, and suitable) to 10 (very unclear, difficult, inaccurate, and unsuitable).

Open-ended interview questions

Table 2.2 displays the questions that participants were asked about each questionnaire as part of the semi-structured interviews. These questions were based on the previous work of a member of the research team investigating perceptions of participants' understanding and interpretation of a questionnaire (Hancox et al., 2015). Each participant was also asked to choose their most and least favourite questionnaire. The responses to the open-ended questions were voice recorded. Based on the principles of Francis et al (2010) it was decided that at least ten interviews would be conducted, and that the point of data saturation would be defined by three further interviews being carried out with no new emerging themes. This was tested by reviewing the data after each successive interview.

Table 2.2: Questions asked in semi-structured interviews

1. Was there anything you found confusing or anything you would change about this questionnaire?
2. What were you thinking about when rating this questionnaire?
3. Are there any sedentary activities that you do that were not covered by this questionnaire?
4. Do you have any other comments about this questionnaire to help us with our research?

2.2.3 DATA ANALYSIS

Questionnaire data were analysed using IBM SPSS version 22. The main analysis involved a 2 Day (weekday, weekend day) by 6 Questionnaire (LASA, Marshall Sitting, IPAQ, MOST, SBQ, SIT-Q) within-subject analysis of variance (ANOVA), with Greenhouse-Geisser correction. Sedentary behaviour assessed by MOST provides an overall score of sitting time for a week. In order to compare values between questionnaires, we have calculated a daily average by dividing the overall score by 7. Given that the MOST does not make a distinction between week and weekend days, the same value for sedentary behaviour was used for both days for this questionnaire. All other questionnaires specify sedentary behaviour during week and weekend days separately. To check for the influence of the MOST on the effect of day, we conducted an additional 2 Day by 5 Questionnaire (LASA, Marshall Sitting, IPAQ, SBQ, SIT-Q) within-subjects ANOVA. These analyses revealed similar findings as those with the MOST included. Therefore, it was decided to report the analyses which included the MOST. Differences in evaluation scores regarding perceived ease and accuracy between the questionnaires were explored using separate 6 Questionnaire (LASA, Marshall Sitting, IPAQ, MOST, SBQ, SIT-Q) within-subject ANOVAs. Where appropriate, post hoc analyses (Least Significant Differences) were conducted. Statistical significance was set at $p < .05$, and η^2 is reported as a measure of effect size with η^2=.01, η^2=.06 and η^2=.14 used for small, medium and large effect size, respectively (Lakens, 2013).

The interview recordings were transcribed verbatim by the first author. Interviews were analysed using the six-stage thematic analysis process shown in Table 2.3 (Braun and Clark, 2006), in order to summarise and identify patterns within the data. The process involved reading the transcripts thoroughly, highlighting statements viewed as significant and those which recurred between different interviews. This allowed the generation of codes to identify interesting features of the data. Initial themes were reviewed by a second researcher, who was not involved in conducting the interviews. The second researcher read through the interview transcripts and the initial coding. They offered feedback on possible overlap of themes and codes to assist with refining the data into broad themes.

Table 2.3: Six phases of thematic analysis (Braun and Clark 2006)

1	**Familiarizing yourself with your data**	Transcribing reading and re-reading the data, noting initial ideas
2	**Generating initial codes**	Coding interesting features of the data systematically across the entire data set, collating data relevant to each code.
3	**Searching for themes**	Collating codes into potential themes, gathering all data relevant to each potential theme.
4	**Reviewing themes**	Checking if the themes work in relation to the coded extracts and the entire data set.
5	**Defining and naming themes**	Ongoing analysis to refine the specifics of each theme, generating clear definitions and names for each theme.
6	**Producing the report**	Selection of extract examples, final analysis of selected extracts, relating the analysis to the research question, producing a report of the analysis.

2.3 RESULTS

2.3.1 PARTICIPANTS

Twelve women and three men participated in this study. The mean age ± standard deviation (SD) of the participants was 49.7 ± 10.2 years (range: 29 – 49 years), PDDS score of 2.8 ± 1.6 (range 0 – 7), and disease duration was 10.4 ± 6.9 years (range: 0.5 – 24 years). The demographic information is provided per participant in Table 2.4.

Table 2.4: Participant demographic information

Study ID	Sex	Age (Years)	Disease Duration (years)	PDDS	Employment
1	F	49	5 years	1	Full time
2	M	48	6 months	0	Full time
3	F	34	8 years	3	Not employed
4	F	51	24 years	4	Full time
5	F	29	18 months	0	Full time
6	F	60	18 years	4	Part time
7	M	68	20 years	2	Retired
8	M	47	8 years	2	Not employed
9	F	59	11 years	3	Full time
10	F	42	6 years	4	Not employed
11	F	45	18 months	0	Full time student
12	F	68	17 years	7	Retired
13	F	48	24 years	6	Not employed
14	F	29	5 years	3	Part time
15	F	69	6 years	3	Retired

Note: PDDS = Patient Determined Disease Steps

2.3.2 SELF-REPORTED SEDENTARY TIME

Mean self-reported sedentary time is reported in Table 2.5. Sedentary time during weekdays ranged between 470 ± 260 minutes per day measured by the MOST and 782 ± 322 minutes assessed per day by the LASA. For weekend days, mean self-reported sedentary time was lower, ranging between 443 ± 287 minutes (IPAQ) and 664 ± 297 (LASA) minutes per day. Values for the MSQ for both weekdays and weekend days most closely mapped to overall mean self-reported sedentary time across the six questionnaires.

Table 2.5: Mean (SD) minutes spent in sedentary behaviours on weekdays and weekend days

Questionnaire	LASA	Marshall Sitting	IPAQ	MOST	SBQ	SIT-Q	Overall mean
Weekday (minutes)	782 (322)	592 (200) $^{a, b}$	484 (248) $^{a, b}$	470 (260) $^{a, b}$	488 (185) $^{a, b}$	716 (236)	589 (133)
Weekend day (minutes)	664 (297)	492 (249) $^{a, b}$	443 (287) ^{b}	470 (260) ^{b}	466 (130) $^{a, b}$	638 (215)	529 (96)

^{a}= significantly different from LASA, p<.05, ^{b}= significantly different from SIT-Q, p<.05

The 2 Day by 6 Questionnaire ANOVA yielded an overall effect for questionnaire (F (3,34) =7.37, *p*=.001, η^2=.362). Post hoc analyses revealed that weekly reported sedentary time was higher on the

LASA and SIT-Q compared with the other questionnaires. No differences were observed between LASA and SIT-Q, nor were the responses on the MSQ, IPAQ, MOST and SBQ different from one another. There was no main effect for day (weekday vs. weekend day: F (1,13) =1.30, *p*=.275, η^2= .091). There was also no significant day by questionnaire interaction (F (3,37) = 0.55, *p*=.639, η^2= .041).

2.3.3 PERCEPTIONS OF THE SEDENTARY BEHAVIOUR QUESTIONNAIRES

Table 2.6 reports the results of the evaluation of the questionnaires as well as the results from the ANOVAs exploring any differences in scores between questionnaires. Results revealed significant differences in the participants' perceived clarity of the questionnaire (F (3,30) = 3.03, *p*=.04, η^2 = .252), accuracy of the questionnaires (F (2,18) =3.87, *p*=.037, η^2=.326), and perceived suitability for their age (F (3,22) = 4.48, p = .015, η^2= .359). Post hoc analyses indicated that overall, the SBQ was perceived to have the clearest instructions and the MOST was perceived as most suitable for people of participants' age. The SBQ and the MOST were perceived to be the most accurate questionnaires. The SBQ was chosen as the favourite questionnaire by 10/15 participants. Not all participants identified a questionnaire as least favourite.

Table 2.6: Mean (SD) evaluation scores for each of the questionnaires and results of Analyses of Variance

Measures	LASA	Marshall sitting	IPAQ	MOST	SBQ	SIT-Q	F-value	p-value	η^2
How clear are the instructions on the questionnaire? [a]	2.57 (1.18)	2.47 (1.55)	2.23 (1.74)	1.96 (1.09)	1.43 (0.51)	2.71 (1.73)	3.03	.041	.252
How easy was the questionnaire to complete? [a]	2.57 (1.76)	2.40 (1.80)	2.89 (2.42)	2.46 (1.69)	1.36[b] (0.50)	3.07 (1.87)	2.09	.129	.148
How accurate an account of your sedentary activities does this questionnaire give? [a]	3.31 (1.49)	3.43 (1.82)	3.00 (2.50)	1.65[c] (0.85)	1.85[d] (1.14)	3.03 (1.56)	3.87	.037	.326
How suitable is this questionnaire for people of your age? [a]	2.43 (1.43)	2.73 (1.76)	3.00 (1.48)	1.50 (0.80)	1.64 (1.01)	3.11 (1.67)	4.48	.015	.359
Chosen as favourite questionnaire by	1	2		2	10				
Chosen as least favourite questionnaire by	2		1			9			

Note: [a] scored on a scale from 1 ‘very clear, easy, etc…’ to 10 ‘very unclear, difficult, etc’, η^2 measure of effect size
[b] Significantly different from all other questionnaires, p<.05
[c] Significantly different from LASA, Marshall Sitting, and SIT-Q, p<.05.
[d] Significantly different from LASA, Marshall Sitting, IPAQ and SIT-Q, p<.05

2.3.4 RESPONSES TO OPEN-ENDED QUESTIONS ABOUT THE QUESTIONNAIRES

Following the six-stage thematic analysis process, three broad themes emerged from the semi-structured interviews: 1) Issues around questionnaire completion and suitability for MS, 2) Feelings about reporting sedentary behaviour, and 3) Recording of additional sedentary behaviours.

1) Issues around questionnaire completion and suitability for MS

Participants preferred questionnaires which were laid out clearly without too many instructions or the requirement for lengthy writing. The SBQ and MOST were viewed favourably because of the grid format, allowing for easy reading and completion for individuals who may experience problems with hand function. *"The tick box answer is really the best for people with (MS). …If you haven't got the mobility skills in your hands it's more difficult to fill in the numbers." Related to SBQ, husband of Participant 13.*

Day to day variability of MS symptoms is significant and the range of activities on any one day was also variable. Participants felt that questionnaire accuracy may be limited by the requirement for data on time spent sitting on an "average day". Some participants also highlighted the questions about employment as not being appropriate for people with their condition. Comments about the limitations of the questionnaires included the difficulty of being precise about numbers of minutes spent sitting or in specific sedentary behaviours (all questionnaires apart from the SBQ). Participants also highlighted unpredictable daily or weekly schedules due to family commitments, work or study patterns, or social activities, may also affect the accuracy of their self-reported sedentary time. *"…Each week is so different, ….so you just spend it on what you do most of the time" Participant 6.*

Participants preferred to break down the time by day, rather than add up sedentary hours over a week as required by the MOST.

2) Feelings about reporting sedentary behaviour

Many participants felt negatively about reporting time spent doing sedentary behaviours. *"It makes me look really lazy because it's all to do with sitting down. Is this because you think that people with MS sit down more?" Participant 15.*

The reporting of sedentary time also emphasised lost activities that participants were no longer able to undertake as a result of their MS. "*It just reinforces the fact that that is a big part of her life, the resting, the napping, the watching the tv….. It's a fact with the MS she can't get up and about and do a lot of things*" *Husband of Participant 13.*

People felt particularly negatively about spending long periods watching the television. *"You look at it and think '70 hours watching the television.' Did I really do that?" Participant 12.*

Some people commented positively however about their enjoyment of sitting to socialise or enjoy a meal. "*Sitting can be quite important….. getting the chance to interact and be a family". Participant 11.*

3) Recording of additional sedentary behaviours

There were also some participants who felt that not all questionnaires included an appropriate range of sedentary behaviours. Additional sedentary behaviours not covered included styling hair, bathing, and other personal grooming tasks. Sitting could also be accrued during caring activities, which were not always covered in the questions. "*When I sit down it's not always for leisure time, I might be feeding my children or changing nappies or playing games which is generally when I sit. To me that's not leisure time but that's the only real way of putting it down*" *Participant 3.*

Browsing the internet on their mobile phone rather than a desktop computer was also mentioned. The MOST and SIT-Q both allow participants to record additional sedentary behaviours not specifically detailed in the questions, which was seen as positive to aid accuracy of the questionnaires as a whole.

2.4 DISCUSSION

Self-reported sedentary time in this group of people with MS ranged between 7.8 and 13.0 hours on weekdays and 7.4 and 11.0 hours on weekends. This amount of sedentary time is consistent with other studies of people with MS which used device-based measures (Bollaert and Motl, 2017, Blikman et al., 2015). The recorded time spent sitting was significantly different between questionnaires, with a large effect size (Lakens, 2013). Opinions of the questionnaires were generally positive with participants rating questionnaires as having clear instructions, giving an accurate account of their sedentary behaviour and being suitable for their age. Due to its clear layout and perceived ease of completion the SBQ was most frequently reported as the favourite questionnaire. The SIT-Q was most frequently reported as least favourite due to its length and the complexity of questions.

For the LASA and SIT-Q sedentary time was reported to be significantly higher compared to the other questionnaires. Differences in the structure and phrasing of the questionnaires may account for some of this variation. The SIT-Q includes the largest number of questions (eighteen questions), and thus more prompts to assist in recalling various sedentary behaviours. The LASA and SBQ are similar in the number and types of sedentary behaviours included, but the LASA has more detailed instructions and requires participants to report the actual time spent undertaking specific behaviours. In the SBQ, participants indicate on a grid the range of time spent in each sedentary behaviour. The ranges vary from 15 min or less to 6 hrs or more. Thus, when a sedentary behaviour is undertaken for more than 6 hours, this is recorded as 6 hours, which can underestimate actual sedentary time. Indeed, one participant stated that she often sits for 7 or 8 hours at work and others indicated watching television for 6 hours or more, leading to a ceiling effect with the SBQ. Variations in reported amounts of physical activity may result from the balance of open and closed ended questions (E et al., 2005), which may impact the data obtained from sedentary behaviour questionnaires in the same manner. Interestingly, the SBQ was the only closed ended questionnaire, reported as the favourite questionnaire by 66% of participants and was highly rated for accuracy. The SBQ may therefore offer a clear and easy method by which people can detail their sedentary activities in future research, particularly when a number of questionnaires are being completed. However due to the ceiling effect, it would be useful to analyse the SBQ data alongside device-based measurements. The MOST, which asks participants to add up overall weekly time spent in different sedentary behaviours was also highly rated for accuracy. The SIT-Q, which was the longest and most detailed questionnaire, was viewed less favourably by participants, being scored as the overall least favourite of 60% of our sample. In contrast, the IPAQ which includes a single question about weekday/weekend sitting was not perceived favourably. Thus, a relatively short questionnaire which covers a range of relevant sedentary behaviours with an easy format appears to be viewed most positively. Assessing self-reported sedentary behaviour by the sum of a number of relevant behaviours has also been shown to have the closest agreement with objective measures (Dall et al., 2017).

Examining individual sedentary behaviours, watching television was the most prevalent behaviour (an average of 3.9 hours per day across questionnaires), which is consistent with other studies (Gardiner et al., 2011, Visser and Koster, 2013). Assessing engagement in other activities such as use of a mobile phone or tablet whilst sedentary, were highlighted by some participants as an omission. This may reflect a shift in behaviours that people do more commonly now than when the questionnaires were first developed. It has been suggested that the range of environments in which sedentary behaviours take place should be considered and should include the workplace, transportation and leisure (Owen et al., 2010). Apart from the IPAQ, all questionnaires do reflect this range of environments. The range of sedentary behaviours proposed in each questionnaire were generally perceived by participants as being appropriate. It is worth noting that three participants specifically mentioned that they liked the opportunity provided by the MOST to record additional sedentary behaviours.

Two questionnaires (the LASA and the SIT-Q) include napping as an example of a sedentary behaviour. Napping is a non-waking behaviour, which is not in alignment with the globally recognised definition of sedentary behaviour (i.e., waking behaviours) (Tremblay et al., 2017). Interestingly napping was highlighted by some participants as being part of living with MS, with 60% of participants reporting taking a daytime nap at some point during the week. However, others felt it was not something they or others their age would do. Analysis showed the MOST, which does not include napping, to be perceived as significantly more suitable for participants' age than the other questionnaires. The LASA and the SIT-Q, the two questionnaires which mention napping, also have the highest reported amount of sedentary time of all questionnaires. However, the average time for a nap was quite short, only 21-25 minutes for the LASA, and 28-30 minutes for the SIT-Q, therefore the higher self-reported sedentary behaviour is unlikely to be due to the inclusion of napping. Misclassification of napping as a sedentary behaviour has been previously reported (Kinnett-Hopkins et al., 2017b), and this highlights the need for the consistency of criteria and to increase awareness of the definition of sedentary behaviour when examining factors related to sedentary behaviour.

Questionnaires which make a distinction between sedentary time during the week and during the weekend are observed to have greater accuracy compared to those that do not make this distinction (Dall et al., 2017). In this sample of people with MS, although the difference between weekdays and weekend days was not statistically significant, participants reported sitting for 72 (± 32) minutes per day more on weekdays than weekends. There was substantial variation between participants in the difference between sedentary behaviour reported on weekdays and weekend days, which could perhaps be due to the employment status of our participants. Indeed, eight participants (53%) reported being in employment or education, and secondary analyses revealed that those who were employed/in education spent less time sedentary for transport at weekends than on weekdays, whereas those not employed spent more time sedentary for transport at weekends. In addition, non-significant differences were found for reading and computer work between employed and non-employed participants. In line with this, Aminian and colleagues (2017) reported that participants who were employed felt that the nature of their jobs, particularly office work, led to higher amounts of sitting during a work day. Differences between sedentary behaviour during weekdays and weekend days have been reported in some studies (van Uffelen et al., 2011) but not all (Visser and Koster, 2013). Differences in waking hours between week and weekend days could perhaps contribute to this (Blikman et al., 2015). None of the surveyed questionnaires asked about length of waking day, and it is not possible to determine if waking day influenced our findings. Variations could also result from different types of social, leisure and transport activities (Lynch et al., 2014) (Visser and Koster, 2013). For example, in our sample 10/15 participants indicated spending more time for meals on weekends compared to weekdays. Further research in a larger sample of people with MS is necessary to explore factors which may influence variability in sedentary time in more detail.

Participants perceived a negative bias about completing all six sedentary behaviour questionnaires together, stating the lack of opportunity to provide a full picture of their daily activities. Some participants wished to report non-sedentary behaviours such as dog walking and housework, as they felt that these were important ways that they spent their time. This is possibly due to the artificial nature of being asked to complete the six questionnaires in one visit, and may not have been the case if asked to complete a single questionnaire, or in conjunction with questionnaires regarding physical activity. However, there is evidence that people with MS share a belief that sedentary behaviour has a harmful impact on their health (Owen et al., 2010)(Owen et al., 2010)(Owen et al., 2010)(Owen et al., 2010). Some were surprised by the length of time that they spent undertaking some sedentary behaviours, particularly watching television and mentioned feeling 'lazy' as they were adding up the hours. Other studies (Greenwood-Hickman et al., 2016, Aminian et al., 2017) similarly found that participants reported having little awareness of the amount of time that they spent sedentary before taking part in the study. Our study did not include any attempts to change sedentary behaviour but several participants stated that they intended to increase their activity levels after taking part. *"Looking at it on paper I've realised …. how long I sit down and that I should make myself move more." Participant 6*

2.4.1 STRENGTHS AND LIMITATIONS

By design this is a detailed but otherwise relatively small-scale study of voluntary participants with MS. It was important to capture the full spectrum of MS reflected in a wide range of time since diagnosis (6 months – 24 years) but as a result there is a degree of population heterogeneity including a broad range of PDDS scores (0 – 7). Overall the majority of participants had relatively low disease severity. Completing six sedentary behaviour questionnaires at one session may also potentially influence answers as a consequence of easier recall and training effects when undertaking subsequent questionnaires, balanced against fatigue. The questionnaires were also completed in the same order by all participants with the longest questionnaire at the end. This could perhaps lead to a more negative emotional state and greater fatigue during the latter questionnaires that were completed.

The self-reported nature of the targeted questionnaires should be acknowledged. As indicated above, underestimation of self-reported sedentary behaviour compared to device-based assessments of sedentary behaviour has been reported in older adults (Gardiner et al., 2011) and people with MS (Kinnett-Hopkins et al., 2017b), even though a moderate correlation was found between objective and self-reported sitting time (Sasaki et al., 2018c). This aspect was highlighted by a number of participants, possibly suggesting an impact from direct or indirect (for example medication related) cognitive difficulties. There may also be overestimation of some sedentary behaviours, when a questionnaire asks for a sum of behaviours during a particular time period or lists activities which could occur concurrently (Dall et al., 2017). However, the advantage of using self-report questionnaires is that information about the types of sedentary behaviour is captured, which could provide important information for the development of interventions to reduce sedentary behaviour.

2.4.2 IMPLICATIONS FOR FUTURE RESEARCH

Future work should combine self-report questionnaires with device-based assessments of sedentary behaviour, to determine which questionnaire represents the most valid assessment of sedentary time for people with MS. The questionnaires focus on overall sitting time, however, there is evidence that the way sitting is accumulated throughout a day has health impacts (Sardinha et al., 2015). The SIT-Q is the only questionnaire to explicitly ask participants about the frequency of breaks in their sedentary time (e.g. less than hourly, hourly, half hourly, every ten minutes, every five minutes). Given that there is some evidence that sedentary time was accumulated in longer bouts in people with MS compared to healthy controls (Blikman et al., 2015, Bollaert and Motl, 2017), it would be interesting to explore if it is possible to assess breaks in sedentary behaviour using self-report in people with MS. Indeed, lack of detail in questionnaires about the length of sedentary bouts and frequency of sedentary breaks was mentioned in one of our interviews as a limitation.

2.5 CONCLUSION

Consistent with other work, this study demonstrates that people with MS report high total daily sedentary time. However, variation in total sedentary time is observed depending on the specific questionnaire employed, the range of questions asked, and the manner in which they are framed. Participants reported the SBQ as the overall favourite questionnaire, due to having a clear layout and providing tick boxes for answer options. Future studies should consider employing both subjective and device-based measures of sedentary behaviour concurrently to determine their level of agreement in measuring sedentary behaviour.

CHAPTER 3: PERSPECTIVES OF PEOPLE WITH MS ON EXERCISE BARRIERS AND FACILITATORS IN RELATION TO A PROPOSED EXERCISE PROGRAMME

ABSTRACT

Background: Despite the known benefits of physical activity and exercise to both physical and mental health symptoms of multiple sclerosis (MS), people with MS demonstrate low levels of physical activity and exercise. Therefore, it is important to understand the barriers and facilitators to exercise when developing an exercise programme for people with MS.

Objective: To discuss a proposed exercise programme with a group of people with MS and through this explore their barriers and facilitators to taking part in exercise.

Methods: Semi-structured interviews and focus groups were conducted with people with MS (n=17) related to a proposed programme of exercise and relevant barriers and facilitators.

Results: Participants mean age was 59.6 (±9.4) years and mean Patient Determined Disease Steps score was 5.0 (± 2.0). An overarching theme of acceptance emerged from this data relating to accepting a diagnosis, lost abilities, and an altered future, and also being accepted into an MS specific exercise group. There were three organising themes: 1) “a very accepting atmosphere”, which encompassed the exercise environment and social support; 2) “future-proof, sustain and build”, related to the effect of exercise on physical and mental health symptoms; and 3) “getting going and keeping going” in which participants discussed methods they used to motivate themselves to continue with exercise.

Conclusions: The findings emphasise the need for knowledgeable health professionals and regular support for participants to ensure exercises are done regularly and correctly. Exercise in an accepting environment was viewed as important, enabling participants to improve both physical and mental health. The social interaction of an accepting group of peers was also perceived to serve as a facilitator.

3.1 INTRODUCTION

Exercise has been shown to have many health benefits for people with multiple sclerosis (MS), including cardiorespiratory fitness, muscular strength (Platta et al., 2016a), fatigue (Latimer-Cheung et al., 2013a), walking speed and endurance (Pearson et al., 2015). Importantly, these benefits are achieved without increasing the risk for relapse in MS (Pilutti et al., 2014). Despite the known benefits, previous studies have identified low levels of physical activity among people with MS (Kinnett-Hopkins et al., 2017b). As well as the physical impact of MS, mental health is also affected, with reports of 22.1% of people with MS showing symptoms of anxiety and 30.5% symptoms of depression (Boeschoten et al., 2017). The UK NICE guidelines on depression in those with a chronic physical health condition highlight the importance of structured programmes of either individual or group-based physical activity to support people to manage their mental health needs (NICE, 2020a). However, exercise programmes for people with MS have shown high drop-out rates (Mayo et al., 2020). Thus, to increase the uptake and maintenance of exercise participation, it is important to understand the barriers and facilitators of exercise for people with MS.

A number of studies have investigated the perceived barriers to exercise in people with MS (Learmonth and Motl, 2016). Barriers to exercise are frequently related to common symptoms of MS. For example, negative experiences of physical activity leading to fear of falling or being injured (Kayes et al., 2011). Fatigue has also often been mentioned as a barrier to being physically active. For example, an experience of worsening of fatigue after exercise induced reluctance to take part in subsequent exercise (Plow et al., 2009). However, becoming more active has been shown to reduce some of these barriers. In qualitative work, people with MS have highlighted the benefits for their symptoms, such as pain and spasms as the most important reason for exercising (Stennett et al., 2017). Other examples include exercise being used as a method to reduce fatigue (Barnard et al., 2020), and improve physical function, such as posture (Crank et al., 2017) and balance (Fasczewski et al., 2018). Indeed, exercise interventions have resulted in improvements in walking speed and endurance as well as fatigue (Pearson et al., 2015, Pilutti et al., 2013b). There is also evidence for exercise improving aerobic fitness, muscle strength, balance, depressive symptoms, and quality of life in MS (Motl et al., 2017c).

Lack of appropriate opportunities to exercise for people with MS was another frequently mentioned barrier. For example, generic leisure facilities having poor access for people with mobility impairments (Borkoles et al., 2008, Plow et al., 2009) or lack of support for those needing assistance to exercise (Borkoles et al., 2008). In contrast, participation in exercise was seen to be enhanced in a suitable environment (Learmonth and Motl, 2016), such as specific MS classes or groups providing peer support (van der Linden et al., 2014). People with MS have reported feeling inadequate or self-conscious when exercising with others at a generic leisure facility (van der Linden et al., 2014), and the value of exercise instructors who were knowledgeable about both MS-related problems and adaptation of exercises for the needs of people with MS has been highlighted (Learmonth and Motl, 2016, Smith et al., 2013). Other reported facilitators to exercise in people with MS included providing a choice of exercises for different ability levels (Learmonth et al., 2013c), exercise instructions and ideas for ways to help maintain an exercise routine (Smith et al., 2013), and feelings of normality and continued physical function associated with motivating oneself to take part in regular exercise (Dlugonski et al., 2012). The importance of providing appropriate support is clear from the evidence that when exercising with suitable support people with MS reported improved quality of life (Learmonth and Motl 2016).

Over the course of their disease, people with MS are likely to be offered many opportunities to take up exercise. Given that positive or negative previous exercise experiences can influence decisions to take up exercise programmes and expectations of the outcomes (Christensen et al., 2016), it is important to understand the prior experience of the individual when planning an exercise intervention. It would therefore be useful to understand more about peoples' experiences in the UK healthcare system, as a number of the more recent studies cited were conducted in the USA, Canada or New Zealand. It is also important to note that the majority of this qualitative research has been conducted in people with relatively low disease severity. Less is known about the perceived barriers to exercise and facilitators for exercise of those with more severe MS. Those with greater mobility disability resulting from their MS are known to be less active (Sasaki et al., 2018b) and therefore may experience different barriers from those who are more mobile. Therefore, the current study aimed to recruit people with MS across a range of disability, to include both those who were currently taking part in exercise and those who were not. Involvement of people with MS in qualitative work relating to exercise will increase the understanding of health professionals of types of exercise chosen by people with MS, and their reasons for participating (Stennett et al., 2017). There may also be reasons that people choose not to participate in exercise and other physical activity which can be explored. Perspectives of people with MS will also serve the purpose of improving knowledge of health professionals around adherence to exercise (Dalgas et al., 2020), an important concept without which the health benefits cannot be achieved. The novelty of this study compared to other studies mentioned above was that participants were asked for feedback about a particular exercise programme and the planned methods to support adherence to exercise. This allowed for more specific feedback which could be used practically to inform the intervention.

3.1.1 AIMS OF THE STUDY

The aim was to explore participants' views on exercise barriers and facilitators as well as their support needs to encourage exercise behaviour. This was carried out via a structured discussion of a proposed exercise programme. Given the objective to inform the development of an exercise intervention targeted specifically at people with more severe MS, the focus was on exercise behaviour (i.e., planned, structured, and repetitive physical activity with the goal of improving or maintaining physical fitness (Caspersen et al., 1985), instead of physical activity behaviour (i.e., any bodily movement produced by skeletal muscles that requires energy expenditure (Caspersen et al., 1985). Information on demographics and current levels of physical activity was obtained, as well as the opinions of participants about exercise. For the analysis, the aim was to explore the meaning and offer some interpretation of the data. Content analysis was therefore discounted as a primarily descriptive approach (Denscombe, 2010). Grounded theory was also considered, whereby data collection and analysis take place in parallel, with each stage of data collection informing the next (Corbin and Strauss, 2008). However, this has been highlighted as a lengthy and potentially challenging process for those, like the author, early in their research career (El Hussein et al., 2014). Inductive thematic analysis aims to analyse data based on its content, rather than on any pre-existing theory or concept (Braun and Clarke, 2013). This method was used in the majority of studies in a metasynthesis of qualitative research relating to exercise in MS, suggesting it is appropriate for this type of work (Christensen et al., 2016). Inductive thematic analysis allows the researchers' interpretation of the data itself to generate patterns and themes, and has been recommended as an accessible approach for less experienced researchers (Braun and Clark 2006). This was therefore chosen as the analysis method. A team approach has been advocated to allow discussion and consensus on codes and themes, thus supporting the trustworthiness of the results (Nowell et al., 2017). The process of inductive thematic analysis also lends itself well to those working in research teams, as in the current study.

3.2 METHODS

3.2.1 PARTICIPANTS

People with MS were recruited from local MS groups, personal contacts and via https://shift.ms/, a website specialising in social networking, information and support for people with MS. Inclusion criteria were a self-reported physician diagnosis of MS, and to be a fluent English speaker with the ability to read and complete questionnaires, as translation services were not available. Those with severe mental disabilities which would affect their participation in an interview or focus group were excluded. Experience of exercise and activity level of participants was not specified with the aim of recruiting a range of levels of activity. Using this diverse and purposive sampling, the aim was to have a sample relevant to the topic of the study and by doing this achieve saturation of the data. Diversity of sampling also supports 'credibility' of the data, with the aim that people with MS reading the report recognise their own experience, adding to the trustworthiness of the results (Nowell et al., 2017). Francis et al. (2010) noted that when conducting interview-based studies the generation of new information began to plateau after approximately six interviews and data saturation criteria were met after thirteen interviews. They chose to stop interviewing after three consecutive interviews without the emergence of new themes. Therefore, the current study aimed to recruit between fifteen and twenty participants to ensure a full range of views were captured. Ethical approval was granted by South Birmingham Ethics Committee.

3.2.2 PROCEDURES

FOCUS GROUPS

Two focus groups were conducted, one at an MS Therapy Centre, one at a hospice where a MS exercise group was being held. Focus groups are a way of approaching a real-life setting, with participants talking to each other rather than a researcher (Kitzinger, 1994). The participants in the focus groups knew each other, which may have been beneficial in encouraging an honest discussion, where the researcher was not known to them.

SEMI-STRUCTURED INTERVIEWS

One of the interviews was conducted face to face, all other interviews were conducted by telephone or Skype. Semi-structured interviews were chosen as they favour open-ended questions and allow the researcher's guide questions to be asked in any order, unlike a structured interview format (Braun and Clarke, 2013). Each interviewee can therefore discuss what is meaningful to them about the topic as the conversation develops. They also allow flexibility and the scope for follow-up questions to explore the topic in more depth.

On attending either the focus groups or interviews, all procedures were explained to the participants and any questions answered. Participants gave written informed consent for their participation. For telephone or Skype interviews participants were sent the consent forms and questionnaires either electronically or as hard copies to complete and return prior to taking part. Subsequently, participants were asked to complete a brief questionnaire pack. After this, the focus groups or interviews were started. All interviews and focus groups were conducted by the author. A topic guide was used (Figure 3.1), which allowed for changes in order and for additional questions based on the participants' answers. All focus group and interview scripts were transcribed verbatim for analysis.

All participants completed a demographic questionnaire which included information on age, gender, ethnicity, educational level, current employment status and time since diagnosis of MS. They also completed two other questionnaires to give further information on their MS, and patterns of physical activity.

QUESTIONNAIRES

Patient Determined Disease Steps (PDDS) (Hohol et al., 1999).

This is used to measure perceived disease severity based on the individual’s mobility. Participants are asked to indicate their own disease severity on a scale from 0 (mild symptoms where activity is not limited) to 8 (confined to bed, unable to sit in a wheelchair for more than one hour). Scores on the PDDS are strongly linked to scores on the Expanded Disability Status Scale, which is assessed by a neurologist (Learmonth et al., 2013d).

International Physical Activity Questionnaire (IPAQ) (Craig et al., 2003)

This questionnaire is designed to measure physical activity levels. It includes sections on work-related physical activity, transportation and housework as well as formalised exercise and sitting. Participants are asked to indicate how much time they spend on these activities each week. The IPAQ is scored by calculating energy expenditure measured in MET minutes (based on a resting activity of 1, minutes of activity multiplied by a factor depending on the intensity of the activity). Walking is classed as 3.3 METS, moderate physical activity 4 METS and vigorous physical activity to 8 METS. Fair to moderate agreement has been shown between scores on the IPAQ and data collected using accelerometers (Craig et al., 2003).

Key questions, *possible prompt questions*

1. **What do you feel are the barriers to taking part in exercise that you or other people with MS may encounter?** *What specifically may put people off exercising? What might help people to overcome the barriers? What are the situations where people might find it more difficult to complete their exercises?*

A general description of the planned exercise programme was given. If appropriate to the venue this included the use of handouts and brief power point slides to give basic information about the exercise component, internet support and monitoring, wall charts and resources to be provided to participants, exercise diaries, goal setting component and related documentation.

2. **Do you have any specific feedback about different elements of the programme?** *Balance exercises – sitting and standing, are they feasible for people with MS? Strengthening exercises – exercises, use of weights, are they appropriate? Cardiovascular – walking as a cardiovascular exercise, how much walking should people be encouraged to do?*
3. **How many sessions per week should people be asked to do?** *Why this particular number?*
4. **Do you think people will be able to carry out the exercises in this programme at home?** *Why/why not?*
5. **What type of support would you normally need from a health professional when taking part in an exercise programme?** *Do you think this is effective? Are there other methods, which you could use to encourage people to adhere to their programme?*
6. **To support our participants we will visit them at home after one week and telephone them after 4 weeks. They will also be able to telephone us if they need advice at any time. Do you think that this is the right amount of support?** *Is there any other support that could be offered to people taking part in the programme?*
7. **Our programme includes goal setting and the use of an exercise diary to record participation in exercise. Have you used methods to record participation in exercise – or to set exercise goals?** *Do you think goal setting will be helpful to people taking part in this programme? How frequently should the goals be set? Are there any specific methods we could use to encourage them to stick to the exercise programme?*
8. **Do you think that using an exercise diary will assist people to stick to the programme?** *Is the paperwork user-friendly, attractive, clear etc?*
9. **Are there any helpful online resources currently available to help you to engage with exercise?** *What are your experiences of using these websites? Do you think an exercise website would be useful to accompany our exercise programme? What other information do you feel should be included on the website? How often do you think that people are likely to use the website?*
10. **Is there any information missing? What other support or resources do you feel are needed by participants in this programme?**
11. **What else do you think would encourage people to take part in this exercise programme?**

Figure 3.1: Interview and focus group questions

3.2.3 ANALYSIS

All transcripts of interviews and focus groups were pooled for analysis. Analysis of the data was carried out using a six-stage thematic analysis process (Braun and Clark, 2006). For this purpose, pseudonyms were given to all participants in order to maintain anonymity. The transcripts were read thoroughly to become familiar with them, highlighting statements of particular interest which were viewed as significant and those which recurred. This allowed the generation of codes, which collated significant data extracts. A complete approach to coding was used, initially incorporating all of the data potentially relevant to the research question and using data-derived codes (Braun and Clarke, 2013). Codes were then grouped together to form sub-themes. The sub-themes were reviewed in relation to the codes. These allowed the building of organising themes which summarised the main findings of the data. Codes and themes generated by the researcher were also checked against the data by the supervisory team. Any discrepancies were discussed and resolved linking the data back to the text thus supporting an inductive approach to the thematic analysis (Braun and Clark, 2006). Themes continued to be reviewed and adjusted throughout the writing of the report based on the ongoing analysis process. A thematic map (Figure 3.2) was created as part of the process, giving a visual summary of the identified themes.

3.3 RESULTS

3.3.1 PARTICIPANTS

Seventeen people with MS took part. Data was collected using two focus groups (one with two participants, one with eight participants) and seven interviews. Table 3.1 shows participant characteristics. Mean (SD) age of the participants was 59.6 (9.4) years, with a mean disease duration of 17.9 (13.0) years and PDDS score of 5 (2.0). All identified their ethnicity as ‘white British’. Ten participants (58.8%) had been educated to undergraduate degree level, with all others identifying a lower level of educational achievement. The majority of participants (70.6%) reported that they were retired or not working temporarily or permanently for health reasons.

Table 3.1: Participant demographic information

Name	Gender	Age	Employment	Disease duration	PDDS	Interview or Focus group
Jane	F	50	Full time	24 years	4	Interview (Telephone)
Mick	M	48	Not working permanent	10 years	5	Interview (Face to face)
Polly	F	53	Part time	2 years	0	Interview (Skype)
Marv	M	64	Full time	7 years	6	Interview (Telephone)
Rod	M	48	Not working temporary	5 years	3	Interview (Telephone)
Riva	F	43	Part time	6 months	3	Interview (Telephone)
Percy	M	61	Retired	10 years	5	Focus Group
Lulu	F	69	Retired	16 years	Not completed	Focus Group
Jack	M	69	Retired	10 years	6	Focus Group
Sally	F	Not completed	Retired	14 years	7	Focus Group
Bill	M	57	Not completed	30 years	Not completed	Focus Group
Vera	F	61	Retired	17 years	7	Focus Group
Minnie	F	Not completed	Retired	Not completed	Not completed	Focus Group
Beryl	F	76	Retired	31 years	7	Focus Group
Yvonne	F	65	Retired	34 years	Not completed	Focus Group
Leah	F	64	Retired	43 years	6	Focus Group
Jude	F	66	Retired	33 years	6	Focus Group
Mean		59.6		17.9 years	5	

IPAQ data showed an overall range of 0 (no reported weekly walking, moderate or vigorous physical activity) to 8040 MET minutes per week (median 1059). These were mainly made up of moderate physical activity within the home (range 0-4800 MET minutes per week, median 240) and moderate physical activity in leisure time (range 0-2880 MET minutes per week). Weekday sitting time according to the IPAQ ranged from 5 hours per day to 16 hours per day (median 12 hours per day).

3.3.2 KEY THEMES IDENTIFIED

There were three organising themes identified in the analysis of the data with titles derived from direct quotations. These were: “A very accepting atmosphere,” “Future-proof, sustain and build”, and “Getting going and keeping going”. Table 3.2 shows the three organising themes, with associated sub-themes, codes and quotes. The overarching theme of “Acceptance” linked to all three as displayed in the thematic map (Figure 3.2).

3.3.3. OVERARCHING THEME – “ACCEPTANCE”

The overarching theme of “Acceptance” linked to the process of acceptance of a diagnosis of MS and uncertainties participants felt about the future, which was evident throughout all organising themes. Being accepted unconditionally by the MS exercise group was seen as important to sustain motivation, generating the theme “A very accepting atmosphere”. The necessity of acceptance was particularly evident in the two focus groups which consisted of people who exercised together. “Future-proof, sustain and build” encompassed attempts at the future-proofing of the body through exercise, linked to the acceptance of a gradual deterioration in physical abilities over time. All participants had faced loss of physical functions, activities, possibly of roles within work and family. The need for and process towards acceptance were encompassed in this theme.

“I’m a bit stubborn, because there’s an escalator and there’s a lift that you can get to go up to the studio, but I still do the stairs. It takes me a while to get up, but I’m determined that I’m going to walk up….” Riva: page 9, line 243

Different attitudes to acceptance and stages of the acceptance journey were evident from the comments and reflected the range of times since diagnosis and physical deterioration experienced. In the theme “Getting going and keeping going” participants accepted the need to be more determined to keep active, in ways they perhaps had not done prior to their diagnosis. Participants also spoke of accepting the need for motivational tips and tools to help them maintain the habit of exercise.

3.3.4 ORGANISING THEME - “A VERY ACCEPTING ATMOSPHERE”

Support from others with MS was mentioned as an important factor to encourage exercise. All participants discussed personal experiences of taking part in group exercise either now or in the past. The value of the MS group setting to encourage sustained exercise participation was highlighted. Participants spoke of feeling empowered to attempt physical tasks after watching others with a similar level of ability.

“I’ve been inspired actually by you Sally, I’ve seen you when you’ve come out of the exercises and you’ve needed the loo. You’ve got out of your wheelchair and you’ve put the brakes on and you’ve pushed it so that you’re leaning. I think there’s no reason why I can’t do that…” Vera: page 6, line 214

Aspects of emotional support when exercising with peers also with MS was also highlighted.

"One of the things I love about here is that I think the barriers have been removed as much as they can. There's a very accepting atmosphere here, they don't judge, whatever you do, exercise, seated exercise if you need it to be. I just find it brilliant…." Lulu: page 1, line 37

However, it was also mentioned that a group could also have negative effect, particularly when considering others more disabled than oneself.

"I think it's put me off going to some MS groups, .. from the pictures I've seen on their news website, …they're all elderly people in wheelchairs. I want to see somebody at my sort of stage, and see how they're getting on with it. Rather than the final stages where they can't really walk." Riva: page 12, line 332

The diversity of a group could be a problem, particularly for younger, newly diagnosed people who may prefer a mainstream class to an MS-specific one. Overall, however, the participants viewed many aspects of group exercise positively.

"I know it's not supposed to be a competition, but you know if gives you something to aim at – put it that way – if you see somebody else is doing more repetitions of something." Marv: page 6, line 226

A competitive element as well as comparison with the physical performance of peers in an exercise class was seen as positive. This increased motivation and encouraged them to work towards goals.

In addition to the MS community, participants also identified support from family or friends as important to encourage them to maintain the habit of exercise.

"I got with a group of friends, not with MS, we used to go swimming or to yoga or Pilates. So you were getting the exercise and you were having a social as well." Jane: page 4, line 132

Support from healthcare professionals or other experts was mentioned as helping to ensure the exercises were done correctly, and also reinforcing the need to exercise regularly.

"I think the fact that… somebody's coming to tell you how to do the exercises. That's important to check that you're doing it right in the first place and then come back again and check that you're doing it right." Jude: page 6, line 196

Experiences of exercising the wrong muscles and being ineffective, and fear of causing harm by doing an exercise incorrectly were identified here. A number of participants spoke of the value of specific one-to-one input from an exercise professional in aiding their confidence and helping them to maintain an exercise habit.

The exercise environment was also discussed including the importance of making the home or gym suitable for the exercise needs of a person with MS. Some participants had areas within their homes which they were able to devote to using for exercise.

"..Having that room set aside will work for me and that will be my dedicated gymnasium… with that gym ball and other things as well that I have picked up over the years and have never bothered using. The motivation is one aspect, but also the practicalities are another aspect." Mick: page 14, line 399

Others spoke of the need for appropriate access for those with disabilities to public gyms, pools, and exercise facilities.

"They've got beautiful disabled changing facilities. You can change but you can't get in the pool. Well you can, you could be thrown in, but you couldn't get out." Lulu: page 3, line 84

There appeared to be a consensus that better consultation with people with disabilities was needed to more fully address their needs when taking part in exercise outside of their homes.

3.3.5 ORGANISING THEME - "FUTURE-PROOF, SUSTAIN AND BUILD"

This theme indicates perceived barriers to and benefits of exercise for people with MS. Exercise barriers can be related to symptoms such as pain and fatigue and their resultant functional difficulties. Perceptions of exercise with MS can also be a barrier. The commonly held view about 'Exercisers' being seen as very fit or portrayed in "lycra" *Jane: page 4, line 132*, was very different to the way participants viewed themselves. This could lead to a lack of confidence to take part for some. Self-consciousness in taking part in exercise, particularly generic classes not designed for people with MS, was also mentioned.

"I realise not everybody's like me, and I was a bit apprehensive, and I was worried about what everyone else would think in the class. Especially going to yoga and Pilates classes, thinking everyone's going to be really fit…" Riva: page 2, line 45

This demonstrates the difficulty expressed by some participants of wanting to continue exercising in a non-MS group, but being concerned about being seen and judged by others.

Despite these perceived barriers, participants related exercising to improvements in their symptoms and general health. The prevention of physical deterioration in one's condition and overall health of the future self were identified as benefits.

"I think just the fact that I'm probably going to get fitter out of it and I'm probably going to be able to keep going longer before I end up in a wheelchair. That's the most important thing for me. And it keeps the brain active." Marv: page 7, line 272

Mental health benefits through taking part in physical activity, even if reluctantly, were another aspect of this theme. Several participants spoke of feeling better through being able to do more activity.

"…Because things are difficult for me to do just walking and things, that then affects your mental state as well; then it's difficult just to live. Strengthening your body and re-educating it, I think that could play such an important part on your mental state." Rory: page 6, line 174

3.3.6 ORGANISING THEME – "GETTING GOING AND KEEPING GOING"

This theme encompasses ways which people had identified engaging in exercise and maintaining their exercise habit. Goal setting was one aspect. People spoke of seeing a change in their ability which encouraged them to continue with exercise. A small number of participants set formalized goals for themselves such as number of steps per day or particular exercise milestones to achieve.

Some participants also spoke of incorporating physical activity into their daily lives.

"Well – I was just thinking that – if you're cleaning cupboards or wiping windows, it's a stretching exercise." Jude: page 2, line 36

Although different from structured exercise, participants described a range of everyday tasks which incorporated physical activity and were viewed as part of their exercise routine.

Different motivational aspects were mentioned. Extrinsic motivation came through various means including having paid to take part in an exercise class or being a member of a sports team. A team was seen as particularly motivating as you were letting others down if you did not attend. Participants discussed the contrast between a supervised exercise class, and finding the intrinsic motivation needed to do their exercises at home. The class was seen to give incentives both to attend and to join in with others, whereas people spoke of finding excuses or other things to do at home when away from peers.

"You get home and you do them for the first couple of days and then suddenly the motivation's gone. Each time I've gone back for physio review, I've always been truthful and said "the biggest problem I find is consistency". You get asked whether you do the exercises and I say "Yes I do but I'm just not consistent enough." Jack: page 7, line 248

This theme also encompasses the feedback participants gave on the specifics of the planned exercise programme and the support they felt needed to be given to aid adherence. The use of visual aids including photographs and videos with real people was seen as key to enforce movement quality and correct techniques for exercises. A number of participants brought up experiences of being unsure if they were exercising correctly or realising later that a technique they had practiced was incorrect.

"I was thinking, "Ah, actually I'm using the wrong muscles, so what I've been doing the last week or so has been completely irrelevant. I've been strengthening my glute, but actually not those muscles to do with my pelvic floor." Polly: page 11, line 314

Participants liked the idea of being able to record what they had done, but generally favoured approaches with minimal writing such as tick-charts or an electronic version where options could be chosen from a menu rather than longer exercise diaries. Some felt cautious about recording exercise where there might be times when progress was limited or the nature of their condition prevented them taking part. Reminders to exercise in the form of emails or text messages were also seen as a way to aid adherence. Variety within the exercise programme was also mentioned to maintain interest over the duration of the programme.

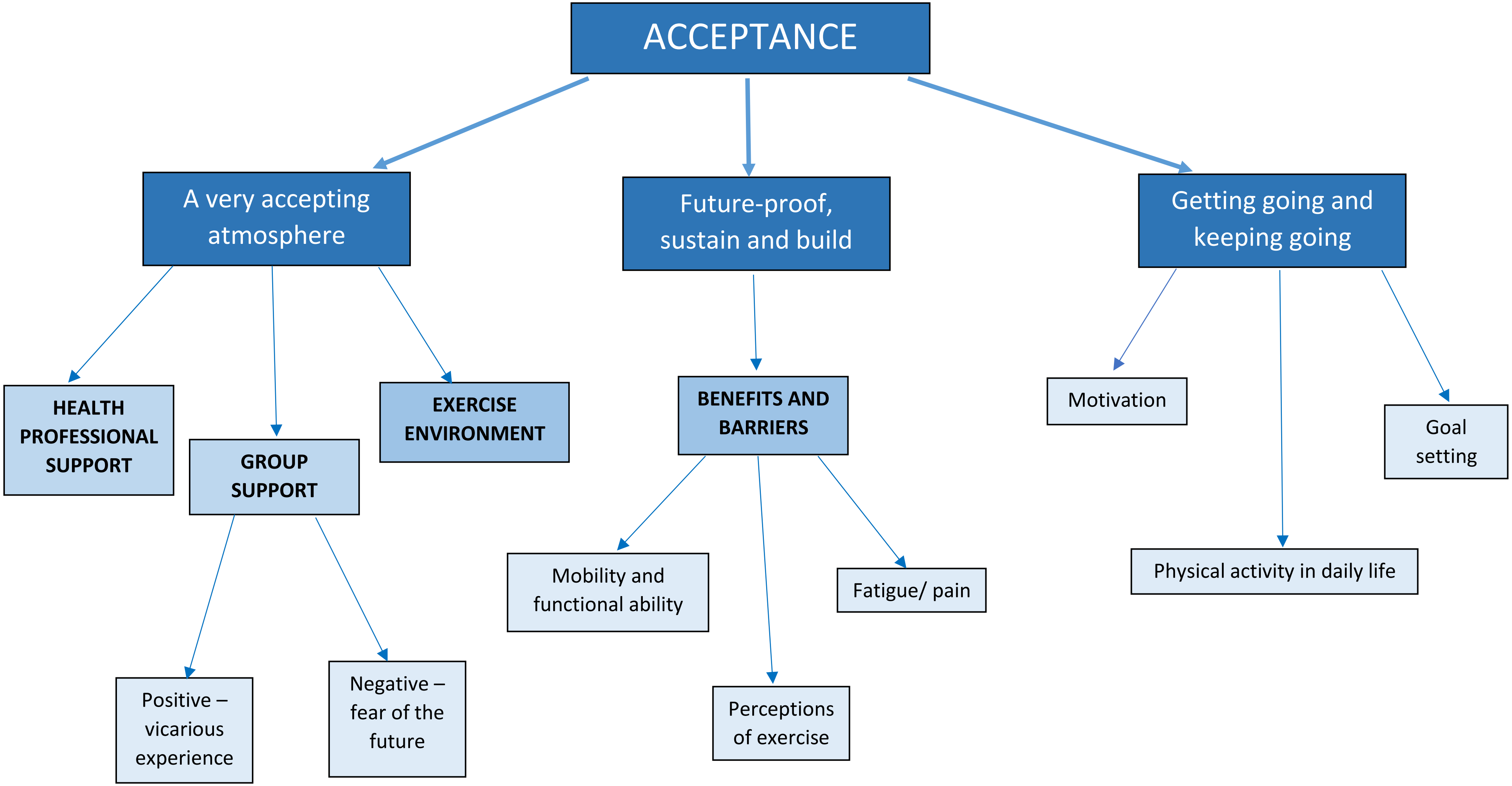


Figure 3.2: Thematic Map
Perceptions on Exercise – People with MS

3.4 DISCUSSION

The findings in this study of a group of people with MS with different exercise experiences revealed three organising themes related to an overarching theme of acceptance. The first, “A very accepting atmosphere” encompassed the acceptance of a group with MS to encourage participation in exercise. The second theme was “Future-proof, sustain and build” which focused on the tangible physical and mental health benefits of exercising. The final theme “Getting going and keeping going” covered the ways people motivated themselves to begin and continue to exercise. The overarching theme of acceptance ran through all three as participants were at different stages of accepting their diagnosis and the resultant changes in aspects of life and activities.

3.4.1 FUTURE-PROOF, SUSTAIN AND BUILD

In line with previous research, a reduction in activity levels after diagnosis even without symptoms was highlighted by participants. Crank et al (2017) described a ‘transition towards inactivity’ with participants perceiving a lowered exercise capacity following a diagnosis of MS, even without specific physical symptoms. Negative feelings were expressed by a number of participants in the current study about completing the IPAQ, which focuses on physical activity. The questionnaire was seen as something which reinforced thoughts and discussion of activities which people could no longer do as a result of their MS. The median score for the IPAQ was 1059 MET minutes per week, corresponding with a moderate level of weekly physical activity (Di Blasio et al., 2016), however there was a wide range of scores from 0-8040 MET minutes, meaning some participants did no weekly physical activity of 10 minutes or more. Many of the participants’ responses referred to the need to accept their own lost abilities. Participants also reported that their reduction in activity levels, early after diagnosis was often due to psychological factors such as a fear of exercising or a lack of knowledge rather than physical problems. However, they highlighted the positive effect of small amounts of both exercise and functional physical activity such as walking, on their symptoms, particularly fatigue, leading to a desire to do more. This was surprising for some, who had expected to feel more fatigued rather than less after exercising, but helpful as a motivator. Other studies have also reported perceptions of this interaction between activity and fatigue, with the positive feelings associated with taking part in physical activity serving as encouragement to be more active (Smith et al., 2013, Kayes et al., 2011). For many of the current participants this was also linked to the theme of acceptance, showing acceptance of the progressive nature of their condition, and the role of exercise as a positive way to manage symptoms. Previous work has also identified the importance of this “future-proofing” (Dlugonski et al., 2012). Overall taking part in even small amounts of physical activity or exercise was perceived to both alleviate symptoms and delay the onset of functional decline.

There was evidence from the participants that they were broadly aware of the benefits of exercise, with many of them mentioning activities such as walking, cycling and attending the gym, which they had enjoyed prior to diagnosis. This suggests the value of independent exercise as a way to self-manage MS. Indeed, a number of studies have successfully supported people to use unsupervised home exercise as a way to increase self-confidence and be empowered to carry out other activities (Thomas et al 2015, Paul et al 2019). Unsupervised home exercise programmes also have the benefit of reduced costs once set up and the potential for use over many years of living with MS. In line with other work (Smith et al., 2013, Crank et al., 2017), participants also mentioned incorporating physical activity in their daily lives through household tasks. Supporting patients to find appropriate ways to add small amounts of physical activity to their day could be reinforced by health professionals involved in exercise programmes in MS. Manns, et al. (2012) suggest that in the least active individuals, health benefits can be achieved by addressing this non-exercise part of the physical activity continuum, i.e., decreasing sitting time or increasing light intensity physical activity. This could be a good way for health professionals to encourage small lifestyle changes, which can be easily carried out at home, and may well have a positive effect on symptoms.

3.4.2 A VERY ACCEPTING ATMOSPHERE

Participants identified both benefits and barriers to group exercise. The value of the group setting for exercise was discussed in relation to being with others with MS with a shared understanding of their condition and its associated challenges. Participants in the current study discussed peer support both for participation in exercise, and for the development of networks outside the class itself. The inspiration offered by seeing others with MS perform both exercise and functional physical activity was highly valued by participants in the current study. This may be due to the relatively high levels of disability among participants, with a mean PDDS score of 5, meaning the majority needed support to walk 25 metres and were likely to use a wheelchair for greater distances. Therefore, observing and learning a movement strategy from a peer could be of greater value to them than to those who were more able. The value of MS role models for general motivation to be more active and as source of friendship and encouragement, were also identified by Learmonth and Motl (2016). In addition, people with MS advocated peer support during exercise to assist in developing pacing and energy conservation skills (Christensen et al., 2016).

Exercising in a group and reflecting on one’s personal progress was viewed as a barrier for some. Participants spoke of the frustration of comparing their present physical ability with sports and activities they could easily and regularly do prior to diagnosis. This is in line with a previous study where people with MS highlighted loss of social connections associated with exercise and also the loss of the enjoyment of exercise itself (Borkoles et al., 2008). Reflection on lost abilities as a barrier to exercising was also evident from the participants in the current study, who gave examples of exercise locations which lacked disability access. These aspects are in line with other literature where psychological, structural and social barriers to exercise for people with disabilities were identified (Smith and Papathomas, 2014). In the current study, participants also highlighted the value of involving those with disabilities in the design of exercise facilities in order to promote an accepting environment.

Views regarding exercise with mainstream non-MS groups were mixed. Similar to other studies (Learmonth et al., 2013c, Borkoles et al., 2008), some voiced concerns about being watched by healthy people as they exercised. Others identified a negative impact of interacting with those more disabled by their MS than oneself. This fear was also identified by Dennison et al. (2010) in a study relating to adjustment to an MS diagnosis, where participants reported to avoid situations where they may encounter those with more severe disabilities. This highlights differences in stages of acceptance of a diagnosis and its preferences for the exercise environment or setting. There was an agreement that contact and interaction with others with MS is valuable if the group setting suits the individual. As well as a suitable group setting, instructors who are trained and experienced in MS can enhance the feeling of safety during an exercise programme (Learmonth et al., 2013c, van der Linden et al., 2014). This supports the importance of health professionals taking time to establish individual needs in relation to exercise programmes. Awareness that exercise and support needs are likely to change during the course of the disease is also key, as the participants in the current study who were at different stages of the disease process showed. Dennison et al. (2010) particularly highlighted participants feeling overwhelmed, afraid and at times abandoned by their healthcare providers in the early stages after diagnosis. This suggests the importance of health professionals being responsive to change when supporting people with MS following diagnosis and referring for exercise interventions.

In line with previous work (Dlugonski et al., 2012, Learmonth and Motl, 2016), the value of friends and family to encourage the uptake and maintenance of exercise was highlighted by participants in the current study. Previous work has shown that fear and anxiety, as well as feelings of lacking relevant knowledge or not being responsible for encouraging exercise on the part of carers, can create a barrier to participation for people with MS (Learmonth et al., 2020). This suggests there may be a need for family and friends to develop knowledge of the condition and how they can best create a supportive home environment. Education of carers has formed a part of the support in exercise programmes for heart failure and stroke patients (Greaves et al., 2016, Vloothuis et al., 2018). This has enabled carers to develop their understanding of the condition and changed abilities of the person, and to provide practical support and encouragement for exercise.

It was interesting to note the varied experiences of support from healthcare professionals during exercise. Crank et al. (2017) also reported a view from their participants of a general lack of advice from health professionals about exercise at the point of diagnosis, and limited demonstration of appropriate knowledge of MS. Diagnosis may be the time at which feeling supported by health professionals is most important, as the therapeutic relationship which can last many years is being established. Following referral to specialised exercise programmes, participants' views of health professionals appear to be more positive. In the current study, people with MS perceived health professionals' feedback on exercise techniques to be helpful, echoing other research findings (Barnard et al., 2020, Christensen et al., 2016). However, perceptions of a physiotherapist having lost interest when a participant was unable to do a particular task were also reported. For the participant concerned, this led to a loss of motivation to exercise. Previous work has highlighted experiences such as these as having a negative impact on future intention to exercise and the expected outcomes of exercise (Christensen et al., 2016). This could also include significant incidents such as injuries taking place during exercise as being unhelpful to encouraging an exercise habit (Kayes et al., 2011). Participants in the current study also discussed a fear of either being ineffective or causing harm by exercising the wrong muscles. In relation to this, people with MS have been found to view building knowledge about the body's response to exercise, appropriate exercise levels, and associated benefits as important (Crank et al., 2017). These educational elements can serve to provide more detailed information about exercise to participants. They also provide a channel of communication to develop rapport. Previous studies which have included education about the benefits of exercise showed over 70% adherence to exercise sessions (Learmonth et al., 2017b, Hayes et al., 2017a) as well as improved confidence and self-reported physical activity for participants (Thomas et al., 2017). This emphasizes the importance of the co-ordinated multidisciplinary approach recommended in the management of MS (NICE, 2014b). The team should demonstrate consistent specialist knowledge of MS, and through this provide suitable support.

3.4.3 GETTING GOING AND KEEPING GOING

Goal setting was identified by some of the current participants both as a way to encourage exercise and in other aspects of their lives such as when completing work-related tasks, however participants did not discuss having set formalized exercise goals with a health professional. In some other studies, goals were behaviour-related, and linked to an action plan, for example participating in a scheduled class over a period of weeks (Learmonth et al., 2013c, van der Linden et al., 2014) or creating a routine which involved exercise (Dlugonski et al., 2012). In the current study, there were similar comments about behaviour-related goals and the value of action planning. Participants identified strategies such as committing to a weekly exercise class or being part of a sports team to encourage participation. For many, an organized exercise activity with others was perceived as easier than finding the intrinsic motivation to exercise independently. Participants also reported feeling positive as they reflected on progress, which encouraged them to continue. This is echoed in other studies with participants citing feelings of accomplishment and self-management (Learmonth and Motl, 2016), and also of doing "normal" things despite having a chronic illness (Dlugonski et al., 2012), as facilitators to continue with exercise. This suggests that there is a need for structure in relation to exercise, of which both goal setting and planning can be a part. The use of supported goal setting has been associated with increases in physical activity (Motl et al., 2017b, Learmonth et al., 2017b) with the potential for these strategies to also foster feelings of control and normality in people with MS.

Other qualitative research has also supported the use of the setting of both goals and plans to support exercise. Kersten et al., (2015b) used both goal setting and action planning in home rehabilitation for people with MS. This was seen as particularly applicable to the home setting and viewed positively by both participants and therapists. In a physical activity intervention, Ryan and colleagues (2017), supported participants with MS to develop skills in coping planning. Results showed that participants had developed coping planning abilities to compensate for periods of inactivity or breaks in their routine such as holidays (Fortune et al., 2019). They perceived coping planning as an important ongoing skill in managing their MS. As another way to support an exercise programme, a number of participants in the current study spoke positively about the use of brief written records such as tick charts, to monitor behaviour. Tick charts were perceived as quick to complete, while the inclusion of space for comments, would also allow for future reference and reflection. Smith et al. (2013) used a more lengthy daily exercise diary. Overall, the diaries were viewed as time-consuming and effortful to complete, with limited scope for the inclusion of problems or setbacks which may limit a person's ability to sustain exercise. This suggests that goal setting, specific types of planning and the monitoring of exercise participation can be positive in fostering a sense of accomplishment following exercise. However, the format needs to be right for the individual. Exercise diaries should allow planning and monitoring of exercise but also encourage people to consider possible barriers during an exercise programme and how these can be overcome.

3.4.4 STRENGTHS AND LIMITATIONS

The study recruited seventeen participants and based on the criteria of Francis et al (2010) thematic saturation appeared to have been reached. All seventeen participants discussed group exercise as being part of their routine either now or in the past so were more likely to be positive and willing to contribute to these interviews and focus groups. Although average age and disability level were high this may have led to a positive bias in the discussions towards the value of exercise, which may not be representative of the MS population as a whole. In an attempt to limit the influence of this, participants were encouraged to consider their own previous and current experiences as well as those of others with MS. The use of both semi-structured individual interviews and focus groups where the participants were known to each other enabled people to express themselves in different ways. It also allowed for the triangulation of data sources to enable a deeper understanding of the topic. For continuity the author alone carried out all focus groups and interviews using a topic guide. The semi-structured nature of data collection means the order of questions asked may differ according to participant responses. However, the author's position as a researcher with a belief in the value of exercise for people with MS is a potential source of bias affecting the way questions were asked. Self-awareness of the author around this bias was an important quality maintained throughout. In order to ensure the data analysis was not affected, the interpretation of the data into codes and themes was carried out jointly with other members of the supervisory team.

3.5 CONCLUSION

This study has shown that exercise was highly valued among this group of people with MS as a way to maintain physical function, interact socially with peers and improve both physical and mental health. The value of a group exercise setting, particularly an MS-specific group was seen as important to encourage participation. However, the way groups are organised and promoted to people with MS should be carefully considered. For example, having a physically accessible environment and being able to exercise with others of a similar ability. The importance of knowledgeable health professionals was identified throughout to support the needs of the individual as they accept lost functions, and develop or continue with lifestyle physical activity and to introduce and reinforce exercise habits. Resource provision should also be considered in relation to the setting and recording of personal activity and exercise goals. Therapist review and correction of exercise technique was also deemed to be key in order to reinforce a programme. However, there was a feeling that some aspects of the ongoing support could be done remotely. This could be key to improving cost effectiveness of rolling out a programme more widely. Based on these findings, a priority for the implementation of physical activity for people with MS should be giving people the skills to monitor their own exercise intensity and progress. The whole of the MS healthcare team, supported by appropriate condition-specific training, should be responsible for promoting an appropriate exercise environment and for ongoing and individualised behavioural support.

CHAPTER 4: PERSPECTIVES OF HEALTH PROFESSIONALS ON EXERCISE BARRIERS AND FACILITATORS IN RELATION TO A PROPOSED EXERCISE PROGRAMME

ABSTRACT

Background: Uptake and maintenance of exercise is low among people with multiple sclerosis (MS). Health professionals are often responsible for referral to and delivery of exercise programmes for people with MS and may have additional insights into effective ways to encourage participation and to support adherence to exercise programmes. Therefore, it is important to understand their views on exercise when developing an exercise programme for people with MS.

Objective: To increase understanding of health professionals' perceptions of barriers and facilitators to exercise for people with MS.

Methods: Focus groups were conducted with health professionals (n=18) working with people with MS related to a proposed exercise programme for this group and their perceptions of barriers and facilitators to exercise for people with MS.

Results: Participants included physiotherapists working mainly in the community (n=10), physiotherapy students (n=3), physiotherapy assistants (n=2), occupational therapist (n=1), researcher (n=1), and exercise instructor (n=1). Mean experience working with MS was 12.0 (± 9.7) years. An overarching theme of communication emerged from the data, relating to how interactions between health professionals and people with MS impact on the provision and support of exercise. The organising themes were: 1)"coping alone and coming together", which related to the challenges of living with a diagnosis of MS, as well as the support offered by health professionals and peers, 2) "expectation creation", was focused on outcome expectations relating to exercise, 3)"push it", related to quality and quantity of exercise, and 4) "especially for you", which encompassed the need for personalisation of exercise programmes and support for people with MS.

Conclusion: These findings suggest that improved multidisciplinary team communication, and also better communication between health professionals and people with MS around exercise would be beneficial to enhance the uptake and maintenance of exercise for people with MS. The results also emphasise the importance of training for health professionals to enhance their awareness of the body's response to exercise and knowledge of effective ways to encourage participation and ongoing engagement in exercise programmes.

4.1 INTRODUCTION

The health benefits of exercise in people with MS are well-established including improvement in aerobic fitness and muscle strength (Latimer-Cheung et al., 2013b). Exercise programmes have also demonstrated positive effects on functional outcomes such as walking mobility (Pearson et al., 2015), perceived fatigue (Pilutti et al., 2013b), and as a promising treatment for depressive symptoms (Dalgas et al., 2015). It has therefore been argued that exercise should be encouraged from early after MS diagnosis (Dalgas et al., 2019). Specific guidelines for people with mild to moderate MS recommend thirty minutes of moderate intensity cardiovascular exercise twice a week, together with twice weekly strength training (Latimer-Cheung et al., 2013a). Research has shown that less than 20% of people with MS achieve the recommended amounts of physical activity to confer health benefits (Klaren et al., 2013). Research has shown that although there is low uptake of exercise programmes, people with MS are aware of the value of exercise for health and wellbeing (Backus, 2016, Crank et al., 2017). Therefore, it is important to look at ways to enhance participation in physical activity in this population.

The perceptions of people with MS towards exercise were considered in the previous chapter. Themes emerged relating to the value of exercise to protect and “future proof” the body, as well as ways to maintain motivation and to incorporate exercise and other physical activity into daily life. The need to create an appropriate environment for exercise which facilitates acceptance of the condition and includes support from health professionals was another key finding. This means it is also important to hear about the views of health professionals on successfully supporting exercise. From first diagnosis, people with MS interact with members of the healthcare team. These professionals are responsible for giving advice about all aspects of their condition, including the referral for and delivery of exercise programmes. Understanding the health professionals’ perceptions of barriers and facilitators to exercise for people with MS can assist in supporting developing and implementing effective exercise programmes.

Previous qualitative work with health professionals has identified the importance of providing choices of physical activity and exercise to people with MS as a key facilitator to support long-term participation (Riemann-Lorenz et al., 2019, Backus, 2016). The latter study focused broadly on physical activity programmes outside the home, but the value of suitable home exercise was mentioned. The data presented in the previous chapter showed perceived benefits of doing exercise at home, but also mentioned problems staying motivated. Programmes have successfully used a range of methods to support peoples’ adherence to exercise (Learmonth et al., 2017b, Hayes et al., 2017a, Carter et al., 2014). As the potential instigators of home exercise programmes, it would be useful to hear the views of health professionals around engaging people with MS in home-based exercise.

Online support for exercise is being more frequently used in MS-based studies (Paul et al., 2014a, Motl et al., 2011). In discussions of the support for MS-focused exercise programmes, previous work has suggested that some patients value these additional methods of support, particularly in remote areas where access to health professionals is limited (Learmonth et al., 2020). In the previous chapter, people with MS were mainly positive about using online methods to access and record exercise. However, limitations of remote contact, such as incorrect movement technique going uncorrected, were identified. People also mentioned not wishing to record participation when fluctuations in their MS led to poor progress. It would therefore be useful to understand more about the views of health professionals working in a range of settings about barriers to exercise for people with MS that they have encountered and their experiences of methods to facilitate adherence to exercise both in-person and remotely.

4.1.1 AIMS OF THE STUDY

The aim was to examine health and exercise professionals' perceptions of facilitators and barriers to exercise programmes for MS. This was done in the context of a specific example of a structured exercise programme for people with MS. Additionally, views were sought on the support needs for people with MS to maintain adherence an exercise programme. The same programme had also been discussed in focus groups involving people with MS. This work was carried out to inform the planning of an exercise intervention for people with MS.

4.2 METHODS

4.2.1 PARTICIPANTS

Health and exercise professionals working with people with MS were recruited through professional networks of the researcher. Inclusion criteria were fluent English speaker with experience as a health or care professional or researcher working with people with MS, to include students who were carrying out dissertation studies into exercise for an MS population. The aim was to gain a range of insights from those working day to day with people with MS, to those who had less clinical experience but were studying the relevant literature in depth. Participants were invited to support the development of an exercise intervention for people with MS by taking part in a focus group or individual interview. As with the qualitative work with people with MS, the aim was to achieve saturation of the data. As before the aim was to recruit between fifteen and twenty participants to capture a full range of views. This was based on the work of Francis et al (2010) who found no new emerging themes, after thirteen interviews, and conducted a further three interviews to confirm data saturation had been achieved. Ethical approval was granted by South Birmingham Ethics Committee.

4.2.2 PROCEDURES

Focus groups were conducted, either at the University of Birmingham or within the NHS Trusts where the health professionals were employed depending on their preference. Focus groups allow participants to talk to each other as well as the researcher, and thus are similar to a real-life setting (Kitzinger, 1994). The participants in each focus group were known to each other as colleagues, which may have helped them to talk more openly. Additionally, three individual semi-structured interviews were conducted, one by telephone and two by Skype. Semi-structured interviews use guide questions, but these can be asked in any order if the discussion warrants this (Braun and Clarke, 2013). They allow a more in-depth exploration of the topic as the interviewee can discuss aspects that are important to them, with spontaneous follow up questions from the researcher. Apart from one of the Skype interviewees, the researcher was known to all participants.

On attending, all procedures were explained to the participants and any questions answered. Participants gave written informed consent for their participation and for voice recordings to be made. For the interviews, which were all done by Skype or telephone, prior to taking part, participants were sent the consent forms and questionnaires either electronically or as hard copies to complete and return. Participants completed a brief demographic questionnaire about their background and experience with MS. This was followed by a semi-structured interview or focus group using a pre-determined topic guide (Figure 4.1). The topic guide questions mirrored those used in the focus groups for the people with MS and were accompanied by examples of some of the resources to be used to support the exercise programme e.g. pictures of exercise examples from the website.

Key questions, *possible prompt questions*

1. **What do you feel are the barriers to taking part in exercise that people with MS may encounter?** *What specifically may put people off exercising? What might help people to overcome the barriers? What are the situations where people might find it more difficult to complete their exercises?*

A general description of the planned exercise programme was given. If appropriate this included handouts and brief power point slides to give basic information about the exercise component, internet support and monitoring, wall charts and resources to be provided to participants, exercise diaries, goal setting component and related documentation.

2. **Do you have any specific feedback about different elements of the programme?** *Balance exercises – sitting and standing, are they feasible for people with MS? Strengthening exercises – exercises, use of weights, are they appropriate? Cardiovascular – walking as a cardiovascular exercise, how much walking should people be encouraged to do?*
3. **How many sessions per week should people be asked to do?** *Why this particular number?*
4. **Do you think people will be able to carry out the exercises in this programme at home?** *Why/why not?*
5. **What type of support would you normally give to people with MS when they are taking part in an exercise programme?** *Do you think this is effective? Are there other methods, which you could use to encourage people to adhere to their programme?*
6. **To support our participants we will visit them at home after one week and telephone them after 4 weeks. They will also be able to telephone us if they need advice at any time. Do you think that this is the right amount of support?** *Is there any other support that could be offered to people taking part in the programme?*
7. **Our programme includes goal setting and the use of an exercise diary to record participation in exercise. Have you used methods to record participation in exercise – or to set exercise goals for people with MS?** *Do you think goal setting will be helpful to people taking part in this programme? How frequently should the goals be set? Are there any specific methods we could use to encourage them to stick to the exercise programme?*
8. **Do you think that using an exercise diary will assist people to stick to the programme?** *Is the paperwork user-friendly, attractive, clear etc?*
9. **Are there any helpful online resources currently available to help people with MS to engage with exercise?** *What are your experiences of using these websites? Do you think an exercise website would be useful to accompany our exercise programme? What other information do you feel should be included on the website? How often do you think that people are likely to use the website?*
10. **Is there any information missing? What other support or resources do you feel are needed by participants in this programme?**
11. **What else do you think would encourage people to take part in this exercise programme?**

Figure 4.1: Interview and focus group questions

4.2.3 ANALYSIS

Focus group and interview transcripts were pooled for analysis. Pseudonyms were given to all participants to preserve anonymity. A six-stage thematic analysis process was chosen for its flexibility, enabling an appropriate level of detail in summarising the data (Braun and Clark 2006). This involved reading the transcripts thoroughly, highlighting statements which were viewed as significant and those themes which recurred. The significant statements allowed the generation of codes. Codes were then grouped together to form sub-themes which gave the key messages from the coding. Linked sub-themes were then grouped together forming organising themes which summarised the main findings of the data. A complete approach to coding was used, beginning with the full dataset and using data-derived codes (Braun and Clarke, 2013). Initial codes and themes generated by the researcher were also checked against the data by the supervisory team with discussion of any discrepancies. Resolving discrepancies involved revising the codes and linking them back to the data, meaning an inductive approach to the thematic analysis was taken (Braun and Clark, 2006). The supervisory team were involved in reviewing and adjusting themes throughout the writing of the report based on continued analysis. A visual summary of the resulting themes was created in the form of a thematic map (Figure 4.2).

4.3 RESULTS

4.3.1 PARTICIPANTS

Eighteen health professionals participated in this study. Data collection comprised five focus groups, two with two participants, two with four participants and one with three participants. The remaining three participants gave individual interviews. Demographic information about participants is given in Table 4.1. Fourteen females (77.8%) and four males (22.2%) were involved. Mean age was 40.2 (± 13.8) years, with a mean experience working with MS of 12.0 (± 9.7) years. Fifteen (83.3%) identified their ethnicity as white British, one (5.6%) as mixed white and Asian, one as Indian and one as Chinese. Six participants (33.3%) had been educated to A-level standard, six to undergraduate degree level, and six to postgraduate degree level. Ten participants (55.6%) were physiotherapists working mainly in the community. Other roles were three physiotherapy students (16.7%), two physiotherapy assistants (11.1%), one occupational therapist (5.6%), one researcher, and one exercise instructor. Ten (55.6%) were employed in the NHS either part or full time, with three (16.7%) self-employed, working privately in the community, four (22.2%) in full time education, and one participant (5.6%) employed at a higher education institution.

Table 4.1: Participant demographic information

Name	Gender	Age	Employment	MS Experience	Role	Interview or Focus Group
Josie	F	51	NHS employed PT	25 years	Community Physiotherapist	Focus group
Fern	F	29	NHS employed FT	9 years		Focus group
Sheila	F	55	Self-employed FT	20 years		Interview (Telephone)
Hilary	F	31	NHS employed FT	10 years		Focus group
Cherry	F	55	NHS employed PT/Self-employed PT	20 years		Focus group
Posy	F	39	NHS employed FT	15 years	Inpatient and community Physiotherapist	Focus group
Andrea	F	25	NHS employed FT	3 years	Inpatient Physiotherapist	Focus group
Carrie	F	42	NHS employed PT	15 years		Focus group
Leanne	F	52	Self-employed PT	15 years	Physiotherapist (MS Therapy centre)	Focus group
Wilma	F	58	NHS employed PT/Self-employed PT	35 years	Physiotherapist, researcher	Interview (Skype)
Alex	M	37	HEI employed FT	9 years	Researcher	Focus group
Adam	M	39	NHS employed FT	5 years	Physiotherapy assistant	Focus group
Lesley	F	35	Full time education	13 years		Focus Group
Brenda	F	62	NHS employed PT	20 years	Occupational therapist	Focus group
Edwyn	M	20	Full time education	6-week placement	Physiotherapy student	Focus group
Lara	F	21	Full time education	6-week placement		Focus group
Dean	M	21	Full time education	None practical dissertation study		Focus group
Rita	F	51	Self-employed PT	2 ½ years	Exercise instructor	Interview (Skype)

Note: FT=Full time PT=Part time

4.3.2 KEY THEMES IDENTIFIED

There were four organising themes identified in the analysis of the data. These were: “Coping alone and coming together”, “Push it”, “Expectation creation” and “Especially for you”. The overarching theme was “Communication” which relates to all of these organising themes with links demonstrated in the thematic map (Figure 4.2). Theme names were chosen with the aim of being concise, creatively grounded in the data, and to give the reader an immediate sense of the theme topic (Braun and Clark, 2006).

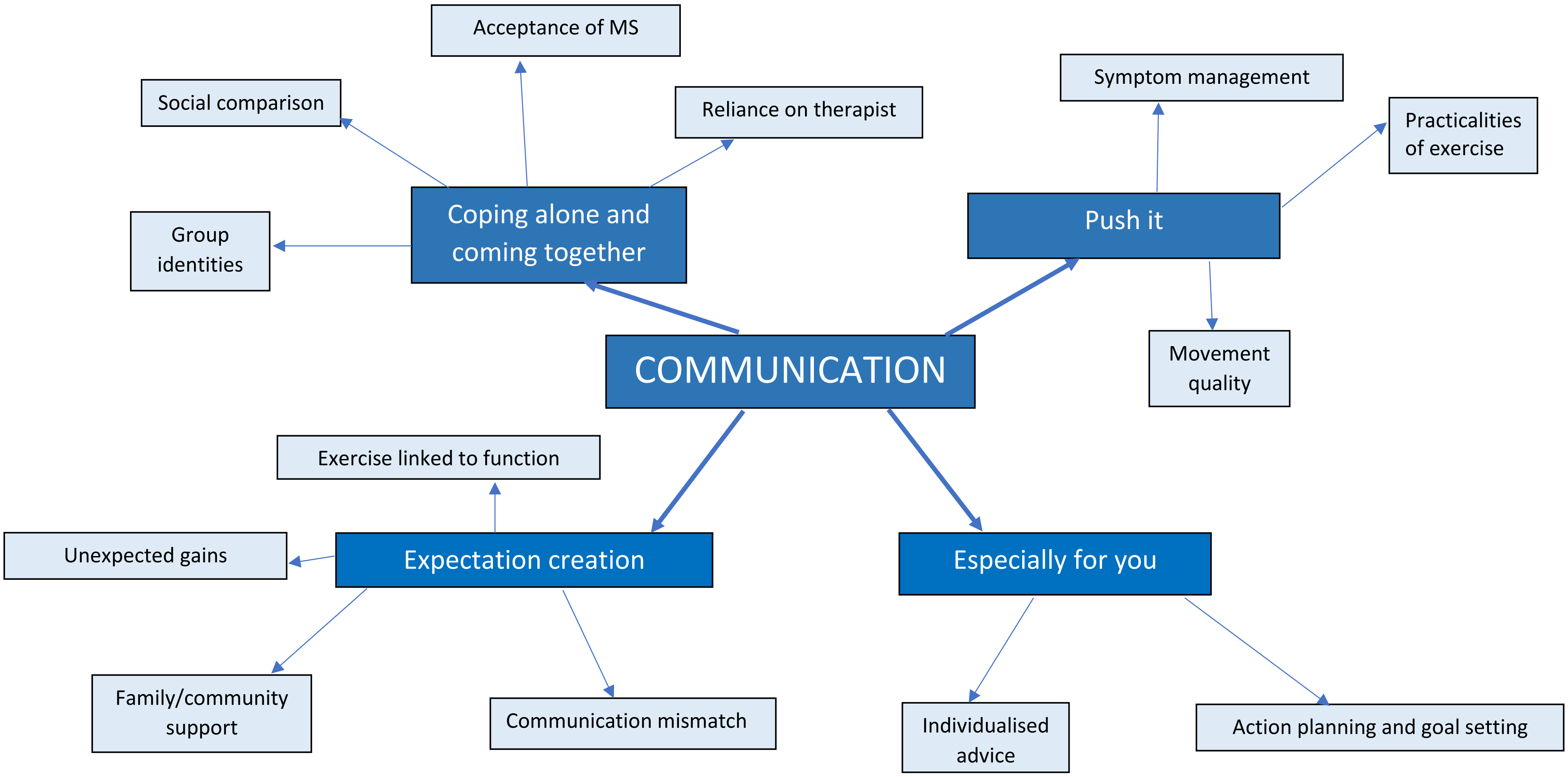


Figure 4.2: Thematic Map
Perceptions on Exercise – Health Professionals in MS

4.3.3 OVERARCHING THEME “COMMUNICATION”

The use of a range of different styles of communication when working with people with MS were evident across the focus groups. Many examples of individualised support and collaborative working with people according to their needs were given, with some participants showing awareness of behaviour change techniques applicable to the maintenance of exercise programmes for their patients. There were also examples of people with MS being viewed as a homogenous group with quotes such as “patients always think…”. “Compliance” with exercise or lack of it was also mentioned suggesting perceptions by some of a negative mind-set from people with MS. Staffing difficulties or a lack of time were mentioned as constraints of NHS practice on communication. Despite these constraints participants spoke at length about the ways in which communication could enhance patients’ experiences. Assisting patients adjusting to a new diagnosis or symptoms, teaching the reasons and value of exercise, and motivating patients to continue with exercise programmes were some examples. Health professionals viewed their own role as sharing knowledge and in turn empowering the patient to develop strategies to manage their condition.

“As they start to learn to cope they are more accepting and acknowledging of their condition and meeting other people. Initially I think it’s being able to find somebody to reach out to, that can give them that guidance and the information that they need without them feeling like they’ve not got the control of what’s going on”. Lesley, page 3, line 117

4.3.4 ORGANISING THEME “COPING ALONE AND COMING TOGETHER”

This organising theme encompasses the health professionals’ views of difficulties experienced by people in coping alone with issues including acceptance of their diagnosis and commitment to exercise. Perceptions of necessary considerations when bringing people with MS together in groups was also captured here. The role of the health professional was seen by some as one of a motivator, working with the individual’s needs to increase self-efficacy.

“I think there are periods of time when symptoms change and psychologically people are affected by that. They can get used to it, they’ve got effective coping cycles, but there will be a period of time where that needs support. That could be self-efficacy theory working in there, for confidence, so that different sources of efficacy need to be targeted in interventions, self-determination theory and intrinsic motivation, what’s meaningful to them. So giving them choice is very important and getting that as a motivating factor.” Alex, page 2, line 57

Perceptions by the health professionals of themselves as experts being relied upon in supporting people to exercise came across in some of the discussions. The pressure of being competent to provide substantial advice and education to people with MS, was one aspect of this. There were also risks of the possibility of dependence on the physiotherapist identified:

"A lot of our patients weren't self-managing and they were reliant on the class. As soon as that class had gone they then had no other output for any exercise or their own rehab, but there were no other services available in our area for them to go to and they weren't good enough to go to a gym or to do other things like that." Andrea, page 2, line 50

This perhaps reflects the way the health professionals communicated with patients, suggesting patients may not have been made aware of the need for them to independently make choices related to ongoing participation in exercise. A preconception by some health professionals of people with MS having a limited understanding of their condition and of the need for exercise emerged from the data. Rather than being actively involved in the management of their MS, patients were viewed by some as passive and lacking in self-efficacy.

"I think in my 35 years of practice, the biggest problem I have with people with MS, is de-conditioning. They're mostly de-conditioned. That's compounding their primary disability. They don't realise that. De-conditioning is insidious, and they don't realise how out of condition they are. You can get them reconditioned a little bit". Wilma page 5, line 128

Within the data there was also discussion of group identity and social comparisons in relation to MS. A number of participants highlighted possible negative views of longstanding MS patients and associated groups by those newly diagnosed.

"But some of those centres – do be a bit careful. Some of those are the longstanding MS's who have been around for ages and the younger, newly diagnosed people don't want to go into that setting." Josie, page 3, line 89

The importance of communication around group membership is evident here. It raises questions about when after diagnosis to introduce a group setting and how its benefits could be communicated better to patients. The mix of longer term and newly diagnosed patients should also be considered in relation to the needs of the individual joining the group. Positive role modelling was also mentioned and the effect this can have on the person engaging with exercise or self-management.

Some of the comments showed perceptions of difficulties such as engaging lifelong non-exercisers. Additionally, the nature of working with MS over many years posed other challenges such as combating boredom with exercise from patients, and gaining the trust of patients who may have better knowledge of MS than the health professionals themselves. The need for appropriate communication was highlighted and therefore different depending on the individual patient.

"..Some of our patients are older. If they haven't really taken up any form of activity when they were younger then as they get older there's less chance they're going to take up some form of exercise programme. The ones that we've worked really well with are the ones who have already been quite active as children or as teenagers. I think it's the same barriers whether you've got a neurological condition or not." Adam, page 2, line 61

4.3.5 ORGANISING THEME "PUSH IT"

The benefits and practicalities around accessing the exercise environment and doing specific exercises, including types and frequency were highlighted by participants. The need for exercise to create a challenge was also identified, coupled with clear communication about the reasons for this to encourage uptake and maintenance of the exercise routine. Both exercise quality and quantity were mentioned.

"*We don't push our patients enough sometimes. Depending on what level your MS is - a lot of my MS's are quite good and you've got to say to them, "10 reps is not enough, 20 reps is not enough. You've got to do these 20 times, times 5, so you're doing it 100 times a day*." *Sheila, page 22, line 632*

In relation to this some participants spoke of the need for an individualised approach taking into account possible physical and mental symptom-related difficulties associated with exercising. The need for specific instruction on how to perform an exercise and teaching awareness of the benefits was clearly seen as the health professionals' role. Many participants emphasised movement quality as a key part of exercise and the need for patients to be educated about this.

"I think that's really important to stress quality rather than quantity. People would think that walking as far as they possibly can without any sticks is a good thing, whereas I might be saying if you can walk with sticks practicing a good pattern that's better. Walk for a shorter distance, have a rest and then walk again, is better than walking a long way and ending up dragging your leg or hitching your hip. The same with the weights if you get a good pattern of movement, it's not about how much you lift. It's important to stress that". Cherry, page 6, line 216

Participants recognised the role of their own communication in developing the knowledge and skill of effective movement patterns. Some identified that patients did not always meet the goals they set for themselves, needing greater encouragement and motivation to continue to exercise. Communication around lack of progress was discussed with many mentioning efforts made to maintain positivity when giving feedback.

"You say 'well actually look you have done less but you've done more resistance and you're working at 56 and that's so much better', 'oh but I didn't do however many kilometres' and it's really hard to try and educate them that actually little and good quality is better." Leanne, page 18, line 525

4.3.6 ORGANISING THEME "EXPECTATION CREATION"

The task of building expectations and sharing how each exercise was relevant to the person's daily routine, functional activities, and life was viewed as part of the health professionals' role. Motivating patients by showing strong links between exercise and benefits to their walking or other daily tasks was mentioned by a number of participants.

"*They might have done quite a bit of this and won't have noticed any change in their timed 10m walk, but it might be a better quality. But what they can do is the functional tasks, personal care stuff which is important to them. If they have got better static sitting balance, then they may be able to dress their upper half …or feel less fatigued doing other activities*". *Leanne, page 22, line 632*

The health professionals, particularly those working in the community, identified their own role in the planning of new routines to include exercise with their patients. Ensuring home exercises were done safely was a need raised by several.

"With a lot of our patients, they have been given exercises from the acute, and then you go and visit them at home and they are trying to get up from a 15-inch sofa and the technique is awful". Hilary, page 10, line 295

A need to bridge the gap between exercises given during a hospital stay and the practicalities of enabling patients to carry them out at home was identified. The value of unexpected functional gains from home exercise which may have a big effect on quality of life was also highlighted by several participants.

"Have you got space for other things that people have achieved? We found in our weight loss programme Club 600, actually other things happened as well. It might be that they've gone swimming for the first time or they've gone on holiday and walked on the beach for the first time, or they've had the confidence to walk to post a letter or maybe they'll go to a dance. It can be a real big thing. Just be open to the fact that something else might happen here. Have some space somewhere in your daily diary for that." Brenda, page 11, line 392

The need for health professionals to have listening skills and to be realistic in discussions about the possible outcomes resulting from exercise was identified, showing in some an awareness of how communicating effectively could provide the necessary behaviour change support.

"*If you say to someone, 'what is it you actually want to be able to do?' and they tell you, and you think 'well actually we are probably not going to be able to do that' or 'that's what we can aim for' but for the interim stage these are the things that you'll need to work on, because those are going to help you to be able to do that. I think it translates it a little bit better for them*." *Leanne page 16, line 473*

The importance of health professionals setting the right expectations and focusing on the likely benefits to quality of life is evident here. Shortcomings in communication between therapists and patients were described, which could lead to poor understanding by patients or a sense of feeling let down when their expectations were not met. Treatment goals which were clear to the health professional but may not be understood by patients were also described.

"We've got our own physio goals and things that we can see a change with and we've got patient-centred personalised goals as well that are probably more functional. A few patients get a bit confused by them." Josie, page 3, line 63

Different health professionals having opposing views on the management of MS symptoms was another example of this mismatch.

"Sometimes the OTs (occupational therapists) are very keen on getting people to conserve energy. We know that the energy conservation techniques have very little effect. What's really effective in fatigue, is exercise. Often, what we're talking about with fatigue is stamina, lack of stamina. It's much harder to sell exercise to somebody who is feeling tired, than it is an energy conservation technique." *Wilma, page 3, line 82*

4.3.7 ORGANISING THEME "ESPECIALLY FOR YOU"

There were discussions around the nature of individualised support and encouragement to keep going with an exercise programme. Participants commented that the content and style of communication should be personalised. The value of incentives, rewards, tick sheets and charts were seen to vary according to patient preference. The way these were introduced and promoted to patients could have a big impact on participation.

"*You do have to have a prescriptive element, otherwise people just don't do it. If they can have a diary say, or something, and they can tick it off and it's something motivational to say that they have done it. Or maybe if they are feeling particularly fatigued, they could still do a session, but maybe it's an easier session. Maybe they cut out a few exercises then they've still achieved it and that still counts as their strengthening day*." *Lara, page 11, line 307*

Participants also offered specific feedback on the planned exercise programme itself and proposed methods of delivery. The use of reminders and prompts to complete planned sessions could form a vital part of therapist-patient interaction during an exercise programme, but needed to suit the individual. The positive and negative aspects of online versus face to face elements of delivery were discussed. Participants also spoke of the importance of how taking part and the anticipated outcomes are "sold" to patients.

"I use texts and I use Skype, and I use email just as little prods. I get people onto apps, perhaps pedometers, where they get feedback, rather than just going on. The other thing that I think really improves in clients, is the salesman approach. It's how you sell the exercise. Most people want to do something with an aim in it". Wilma, page 4, line 116

The value of family support and communication to support ongoing exercise participation was also mentioned. A number of participants felt that promoting and teaching home exercise programmes to family members was as important as to the person with MS.

"Maybe it's giving the family the opportunity to be there…seeing how they could help – could they go for a walk with them? Would that make the difference to them actually going out and doing that walk for ten minutes? Or would they go a bit longer if someone went with them?" Josie, page 4, line 119

Some also mentioned the value of creating an environment to allow communication between family members and carers.

"We had never anticipated the social aspect of it either really. I mean that seemed to be as big a thing particularly for the carers that used to come because it almost became, one room was for the people exercising and the other a carer support." Leanne, page 3, line 70

Health professionals were aware that the need for support went beyond just the patient themselves. Fostering communication among the carers was seen as an additional part of meeting the exercise needs of the patient.

4.4 DISCUSSION

4.4.1 COMMUNICATION

This study aimed to examine health professionals' perceptions of facilitators and barriers to exercise for people with MS. Communication was the overarching theme. There may have been individual differences in styles of communication as the sample consisted of students, experienced practitioners who had a role in education as well as those who did not. Communication was seen as both a facilitator and a barrier to the effectiveness of exercise programmes for people with MS. Effective communication between health professionals and people with MS could create a supportive environment for people adjusting to a diagnosis and new symptoms, as well as aiding the uptake and long-term maintenance of exercise programmes. Shared decision-making has been advocated as a communication technique to enhance collaboration between patients and physiotherapists and improve patient satisfaction (Hoffmann et al., 2020). Health professionals in the focus groups described examples of shared decision-making from their own practice, including honest discussions with people with MS about the expected outcomes of exercise and the setting of realistic goals. Examples of poor communication affecting participation in exercise were also evident from the current data. For example, participants spoke of patients being offered exercise programmes as inpatients in acute care which were then unsuitable for them to do at home. A meta-synthesis of factors influencing exercise for people with MS described this ‘one size fits all’ approach as having a negative impact on the intention to exercise and execution of exercise programmes Christensen et al. (2016). Ways of avoiding a ‘one size fits all’ ethos could include more individualised communication, which needs to be advocated within the education of healthcare students. The inclusion of patient representatives in giving feedback and contributing to the design of services would also support more person-centeredness.

Health professionals who participated in the current study also discussed the role of communication with carers. Carers were viewed as an important group who also need to be educated in the benefits of exercise and themselves supported to promote this in people with MS. Increasing the knowledge of carers has already been recognised as a way to motivate people with MS to become more active (Learmonth et al., 2020). In one qualitative study people with MS attended focus groups with their carers to discuss their experiences of physical activity. Results highlighted the broader role of carers working together with people with MS to support increasing lifestyle physical activity, as well as joint problem solving to cope with declining abilities (Fakolade et al., 2018). Education of carers around the importance of exercise and how to support their significant other has also been used in home rehabilitation in other populations. In one study, carers were provided with a tailored manual to aid their understanding of heart failure and ways to help their friend or family member’s home-based rehabilitation programme (Greaves et al., 2016). Compared to a usual care control group, this intervention significantly improved disease-specific quality of life (Dalal et al., 2019). Another programme has involved carers for people following stroke being trained to assist their family member in a range of functional exercises at home, with remote support being provided by a mobile phone application (Vloothuis et al., 2018). Results of an 8-week pilot showed time spent on home exercise was increased by almost 150 minutes per week. These results suggest that the involvement of others, whether, friends, family or carers can be important in supporting particularly home exercise programmes, where there is less contact with the therapists delivering the exercise. This warrants further study in people with MS. However, it is important to note that the involvement of carers to support exercise in this way may not be appropriate to those with more mild disability from their MS who may prefer a self-management approach.

Communication within the multi-disciplinary team was another element discussed by the health professionals in these focus groups. Some of the health professionals who participated were critical of the knowledge of their colleagues in other professions. Fatigue management was one example where physiotherapists promoted exercise while occupational therapists encouraged limiting activity to conserve energy. There are NICE guidelines for the management of MS (NICE, 2014b) which provide a framework for the services in which many of these health professionals work. These guidelines endorse the effects of exercise to help symptoms. The health professionals who participated were positive about exercise, however evidence suggests that people with MS are not receiving a consistent message about the value of exercising. The UK's professional body for physiotherapists, the Chartered Society of Physiotherapy (2020) recognises a gap in skills in both prescription and progression of exercise among members, highlighting exercise as a key area for student teaching. Research from the perspective of people with MS has shown that exercise was rarely mentioned by neurologists in particular (Crank et al., 2017, Kayes et al., 2011) leaving them unsure as to whether exercising was allowed or safe for them. Results of another study showed that people with MS viewed health professionals as generally encouraging of exercise but not able to offer specific guidance to them (Learmonth et al., 2017a). A lack of knowledge about the health benefits of physical activity, and confidence in communicating this to patients appears to be widespread among medical doctors. Studies have shown that medical student teaching about the promotion of general physical activity is inconsistent across courses (Chew et al., 2019) and that knowledge of physical activity guidelines among hospital doctors of all grades is poor (Cuthill and Shaw, 2019). It is therefore not surprising that in primary care, although physicians agreed that physical activity was important, a lack of knowledge is cited as a barrier to promoting physical activity to their patients (Hébert et al., 2012). When the medical professionals often lead the healthcare team this lack of recognition of the value of exercise could create a perception that physical activity and exercise are not relevant in the management of MS. These wider attitudes could make it harder for physiotherapists, and other team members to do the job of promoting the benefits of exercise for MS symptoms, and do not fit with the co-ordinated multidisciplinary approach which is recommended (NICE, 2014b).

NICE guidance also endorses the use of behaviour change approaches to support ongoing exercise after programmes have ended, and for all health professionals involved to receive specific training (NICE, 2014a). Despite this, the current results showed that the health professionals who participated lacked expertise in the use of behaviour change techniques to support exercise. The theme “Especially for you” showed some awareness of methods such as goal setting, social support through exercising with a partner and the use of exercise reminders. However, some participants spoke of people with MS wanting to improve physically but being unwilling to exercise, or unable to exercise independently. In these cases, in order to increase motivation and enhance self-efficacy for people with MS, a more detailed knowledge of behaviour change theories and how to link these to behaviour change strategies would be useful. Behaviour change does not appear to be a routine part of physiotherapy education with a study of practice tutors showing a lack of teaching about behaviour change in the undergraduate curriculum (O’Donoghue et al., 2012). Qualified physiotherapists’ use of behaviour change techniques as part of interventions to promote physical activity in routine clinical practice was also found to be limited. A systematic review of practices of physiotherapists found only seven behaviour change techniques used across three observational studies, the main techniques being goal setting and social support (Kunstler et al., 2017). The lack of knowledge about effective ways to support behaviour change has also been acknowledged by health professionals themselves (Keyworth et al., 2019). This emphasises the need for education around behaviour change across health professions, which could help to reinforce health promotion messages when people with MS come into contact with different members of the multidisciplinary team.

4.4.2 COPING ALONE AND COMING TOGETHER

The health professionals who participated in this study showed some awareness of patients’ need for self-efficacy in order to successfully undertake a programme of exercise. Earlier work has recommended education to improve self-efficacy as one of the key strategies to increase physical activity participation in people with MS (Backus, 2016). This links with the Health Action Process Approach (HAPA) a model of health behaviour change in chronic disease (Schwarzer et al., 2011), in which the need for self-efficacy at all stages is emphasised. Some of the health professionals in the current study acknowledged their role in the development of patients’ perceived self-efficacy in relation to both adjustment to a diagnosis of MS and managing symptoms, and to carrying out exercise programmes independently. Fasczewski et al. (2018) found that autonomy in managing their MS and making choices about physical activity was a key element for long-term adherence to exercise in patients. Only one participant in the current study mentioned offering choice as a way of supporting independence in exercise. However providing information and choice is recognised as a way to develop an autonomy supportive environment, and therefore improve the quality of motivation (Williams et al., 2006). In relation to ‘coping alone’ in this theme, having intrinsic motivation and thus feeling more able to cope without the support of the health professional makes a desired behaviour change more likely to occur (Williams et al., 2006). Health professionals in the current study spoke of taking time to understand the patient’s perspective. This is another way an autonomy supportive environment can be fostered (Williams et al., 2006, Soundy et al., 2016). Specific training for health professionals in how to create an autonomy supportive environment could also form part of education around behaviour change as previously discussed.

In relation to ‘coming together’, current participants also discussed the use of exercise groups specifically for people with MS. Concerns were raised that particularly newly diagnosed patients would not wish to attend a group with more disabled people, for fear of what their life may become. These concerns around social comparison are echoed by Dennison et al (2010) describing patients not wanting to be reminded of the severe disability which can result from MS. Ultimately this could result in people not engaging with exercise classes, which may be the only supported option available to them. The provision of unique understanding, and practical advice by others with MS in a group setting was also identified by Dennison et al (2010). In the focus groups with patients in the previous chapter, people with MS also reported mixed views on group exercise. For some, social comparison was seen as difficult, particularly encountering those more disabled than oneself. However, others highlighted the importance of the peer support provided by other members of the MS group. Health professionals therefore need skills in assessing the suitability of individuals with MS for groups, bringing them together where appropriate and also how to guide the groups so that they are supportive to members.

4.4.3 PUSH IT

Participants in the current study spoke of the need for exercise to create a challenge to the body’s balance mechanisms, muscles and cardiovascular system, in order to have the desired health benefits. They also recognised a myth still perpetuated by some professionals that exercise can cause harm to people with MS. This was echoed in other research with examples of different messages being given out by different experts. This included reports of neurologists telling patients to “take things easy” (Riemann-Lorenz et al., 2019), and beliefs of some health and fitness professionals that exerting energy is not appropriate for people with MS, leading to them being over-cautious in their exercise recommendations (Backus, 2016). From current participants, the consensus appeared to be that people with MS needed to be doing more. However, this was coupled with the awareness of symptom-related barriers. Backus (2016) concluded from her review that people with MS believe they will benefit from being more physically active, but are prevented from doing so by a fear of relapse. This shows evidence of the need for the health professionals to use behavioural support to develop self-efficacy around exercise. Mastery experience (Bandura, 1997) can be used to develop this. Feedback and support for quality of exercises would appear to be a key part of developing mastery and to lead to a better motivation, supporting the achievement of exercise goals. Previous research from MS patients has shown a desire for very specific information around exercise relevant to managing symptoms, and appropriate for different levels of disability (Learmonth et al., 2017a). It may be that the importance of quality is not emphasised enough by health professionals when a programme is recommended. Exercises done poorly are less likely to achieve the desired results. Education around the need and appropriate time for exercise progression, and verbal persuasion of the relevant health benefits also supports self-efficacy (Bandura, 1997). This further highlights the need for behavioural support from health professionals in enabling participants to develop independence in exercise technique and progression.

4.4.4 EXPECTATION CREATION

The management of expectations around exercise was seen as a key role of health professionals by the current participants. Some participants highlighted a lack of patient knowledge about managing the expected short-term effects of exercise, such as tiredness or an increase in body temperature, as being a barrier to long-term participation. Similarly both, Christensen et al. (2016) and Kayes et al. (2011) reported a need to manage these immediate effects from exercise in order to achieve the expected longer-term outcomes of improving general wellbeing as well as symptoms such as balance and fatigue. Establishing, and if necessary correcting, patient expectations about the effects of an intervention is a part of shared decision-making (Hoffmann et al., 2020). A number of participants in the current study did discuss both making exercise activities safe and relevant to an individual's daily functions, and of ensuring that expectations are realistic. For example, enabling them to see how carrying out a strengthening exercise such as a straight leg raise may help their goal of a better sit to stand, and encourage continued participation in the exercise programme. Riemann-Lorenz et al. (2019) also highlighted the importance of positive experiences with physical activity to facilitate skills for long-term adherence to exercise in people with MS. This has been echoed in other research with participants citing both physical and mental health benefits which encouraged them to maintain an exercise routine (Fasczewski et al., 2018). Overall it is the responsibility of the health professional to manage expectations relating to exercise. Skilled communication can assist with the discussion of what can realistically be achieved in both the shorter and longer term i.e. meaningful and feasible goals for the patient. This can serve to enhance patient motivation and self-efficacy.

4.4.5 ESPECIALLY FOR YOU

Support methods identified in the current study also included the setting and reviewing of personalised goals, and the showing of ongoing support from health professionals through regular contact such as reminders to exercise. These patient-centred interactions are conducive to creating an autonomy supportive environment (Soundy et al., 2016). In relation to information provision around exercise, participants suggested that this should be tailored to the individual as not all patients would be confident accessing information via the internet. Participants valued the use of visual cues or simple pictures either online or in a booklet, showing correct exercise technique. This personalised support can serve to both save time for the health professional and may also reduce the need for people with MS to travel to community exercise facilities. Having to travel to access exercise is known to create difficulties for people with MS and their carers (Backus, 2016, Learmonth et al., 2020). The latter study was conducted in a remote rural community with little face-to-face exercise provision. Their participants, who included patients and carers, recognised the benefits of online classes in real time, provided they could use the technology, which would create a similar structure to attending a centre-based session. However, in-person interaction, even if infrequent was valued above online. Crank et al. (2017) found that their participants with MS cited difficulties with maintaining self-directed exercise at home, and similarly some of the current participants identified a lack of social support as a potential barrier to home exercise, although they endorsed the home environment as a safe place for exercise to be carried out functionally. These results further support the use of an individualised approach to the provision of information and support, particularly considering people with MS span the age groups, activity levels and will have varied likes and preferences.

4.4.6 STRENGTHS AND LIMITATIONS

The researcher as a health professional conducted all the interviews and focus groups and aimed to be aware of their own biases. Attempts were made to mitigate bias by recruiting other disciplines to the focus groups and interviews. A supervisory team with expertise in psychology and qualitative research also provided diversity of expertise when analysing the data. The use of a pre-determined topic guide also aimed to ensure consistency in the approach to questioning. Being known to the majority of participants may have assisted with open discussion, but could also have created a limitation. A range of levels of experience working with MS was included in the sample, from students without hands-on experience in an MS setting to physiotherapists practicing for 35 years. However, this meant that the results reflected a diversity of experience levels rather than an in-depth view of participants with a particular amount of experience. All participants showed interest and enthusiasm for the topic. There may have been interventional consequences, particularly for the physiotherapy students who participated. The discussion and deeper thinking promoted may have had an effect on future practice.

4.5 CONCLUSION

This study has shown that communication was seen as both a barrier and facilitator to exercise in people with MS. Health professionals who participated identified examples where good communication could both support adherence to exercise and the associated functional benefits, and provide emotional support when adjusting to disease fluctuations. The importance of the right resources to support exercise, both internet-based and via more traditional methods was also highlighted. Poor communication within the multidisciplinary team could also create a barrier to exercise. There was some evidence of limitations in the knowledge of the health professionals, around exercise itself and methods to support behaviour change. Other barriers which emerged included a mismatch of expectations around exercise between health professionals and patients, and a lack of suitable exercise choices being offered. The addressing of training needs of all health professionals relating to exercise, and support for behaviour change could assist in facilitating wider exercise options for people with MS.

CHAPTER 5 – INTEGRATION OF FINDINGS RELATING TO PERCEPTIONS ON A PROPOSED EXERCISE PROGRAMME OF PEOPLE WITH MS AND HEALTH PROFESSIONALS

ABSTRACT

Objective: Qualitative data has been collected from health professionals and from people with multiple sclerosis (MS) relating to their perceptions of barriers and facilitators to exercise in relation to a planned exercise programme. The aim of this chapter was to integrate the findings of chapters 3 and 4 to produce further recommendations for the delivery and support of exercise for people with MS.

Main discussion points: There was evidence of shared perceptions of people with MS and health professionals who participated. This was shown in the interaction between the overarching themes of acceptance and communication. The need for health professionals to use communication and behaviour change support which is appropriate to the patient's stage of acceptance of their condition was therefore identified. The importance of patient-led goal setting for both exercise behaviour and outcomes was also mentioned by both groups, as well as difficulties achieving goals. This led to the recommendation of support for goal setting as well as action planning and coping planning. Both MS patients and the health professionals also acknowledged the value of social support from family and friends or via an MS group.

Conclusions: Developing strong communication between the patient and therapist can encourage shared decision making, and support self-efficacy. Health professionals could develop their knowledge and application of behaviour change techniques, enabling behaviour change support to be adapted according to the person's activity level, acceptance of their condition, and individual preferences.

5.1. INTRODUCTION

The preceding two chapters have reported perceptions of barriers and facilitators for exercise for MS based on focus groups and interviews with people with multiple sclerosis (MS) and health professionals working with MS. Organising themes of the data from people with MS related to the creation of an accepting atmosphere for exercise, ways of motivating oneself to exercise and future-proofing the body through exercise. The overarching theme from the people with MS was "Acceptance". Organising themes from the health professionals linked to the topics of coping alone and coming together with the MS community, the creation of expectations and practicalities relating to exercise, and making the exercise specific to the individual, with an overarching theme of "Communication". This chapter aims to discuss the qualitative findings of both chapters together.

5.2 ACCEPTANCE OF A DIAGNOSIS OF MS AND ASSOCIATED LIFE CHANGES

Acceptance was the overarching theme of the focus groups conducted with people with MS. Based on their different experiences including interaction with health professionals, participants showed variation in how they accepted their MS diagnosis. This acceptance of MS in turn influenced their perceptions of barriers and facilitators to exercise. Based on the acceptance stage of the patient, communication from health professionals should therefore be adapted for their individual needs. A review highlights the process of learning to live with chronic illness, suggesting that health professionals may favour the “traditional” approach that when people are diagnosed, denial of the illness is followed by a process leading to acceptance Telford et al. (2006). These authors advocate health professionals seeking to understand the experience of chronic illness from the perspective of the person, thus hearing individual stories and narratives which can be missed (Telford et al., 2006). Dennison et al. (2010) suggest that in an illness such as MS, which affects individuals very differently across the lifespan, there is a lack of certainty about the future. When the things a person needs to adjust to or accept are not clear, a range of strategies are applied at different stages (Dennison et al., 2010). The paper refers to strategies including a positive outlook, information seeking about MS, and social support. In the current study participants also referred to personal coping strategies, which included support from others and remaining positive despite setbacks. Within the theme “Especially for you”, health professionals who participated also acknowledged the differing needs of individuals over the course of their disease, meaning the type of support for exercise required may also change.

5.3 THE IMPORTANCE OF COMMUNICATION

Communication was the overarching theme of the health professionals’ focus groups. The importance of good communication to provide individualised support according to need and from diagnosis was recognised. Both health professionals and people with MS identified ways which communication could change an experience of exercise positively. Examples were given by the health professionals of using communication effectively to motivate patients to continue with exercise. People with MS praised an accepting atmosphere in some exercise groups which encouraged participation without judgement. There were also negative examples, a lack of communication between acute and community healthcare being mentioned by the health professionals. A person with MS noted their perception of a physiotherapist losing interest when they could not perform a particular exercise. Conversely, some of the health professionals spoke of people with MS wanting to improve their physical function, but not being prepared to be challenged by exercise. These miscommunications can be avoided by the health professional more plainly stating their expectations, and the person with MS being clearer about their capabilities. Indeed in the current study, health professionals used the term “compliance” in relation to people with MS participating in prescribed exercise programmes, showing evident discomfort with those who chose not to comply. Chakrabarti (2014) describes compliance as “the extent to which the patient’s behaviour matches the prescriber’s recommendations”, highlighting the expectation that the patient would carry out a recommended behaviour, and suggesting disapproval of behaviour which does not comply. It may be that greater psychological flexibility and resilience is needed on the part of health professionals to deal with the discomfort of those who do not wish to take their advice. Chakrabarti (2014) discusses the use of “concordance” as an alternative. The concept of concordance, it is argued, recognises that there may be differing views between patients and health professionals, but that a strong therapeutic relationship, based on good communication can result in decisions which consider both perspectives (Chakrabarti, 2014). One study around goal setting in MS (Bloom et al., 2006), sought to measure concordance, with results highlighting a disparity in the views of people with MS and health professionals. In this study the patients chose different goals from the health professionals and also gave higher ratings to the likelihood of their goals being achieved (Bloom et al., 2006). Other work involving people with low back pain has compared patient-prioritised and led exercise goals to a usual care group receiving only therapist-prescribed exercise. This study found better outcomes for disability and pain as well as self-efficacy and quality of life in the patient-led goals group (Gardner et al., 2019). In the current study, there was evidence of shared perspectives from the two groups, for example on ways to incorporate physical activity or exercise in their everyday life. People with MS discussed fitting short spells of exercise into brief periods of spare time such as when cooking. Some of the health professionals also identified a similar practice of encouraging people to carry out short sessions of exercise activity such as balance training, in spare moments throughout the day. This suggests the potential of strong communication between the two to bring these shared views together, supporting exercise which is relevant to the individual.

The example of a perceived loss of interest from the physiotherapist illustrates the longer-term effect of communication between people with MS and health professionals. The impact of the ‘relational’ connection or lack of one, between healthcare professionals and people with MS is explored further by Soundy et al. (2016). Their meta-synthesis highlights the need for health professionals to acknowledge the importance of these interactions and demonstrate listening skills and understanding of the person (Soundy et al., 2016). Similarly other research has emphasised the patient-therapist relationship, formed at the first meeting, highlighting the importance of the therapist’s listening skills, making the person with MS feel they are treated as an equal in conversations, with their wishes and preferences respected (Christensen et al., 2016). It is evident from both the people with MS and the healthcare professionals in the current study that the connection between them is essential for the success of any exercise intervention, from ensuring exercises are done correctly, to the provision of reminders and prompts, to behaviour change support for ongoing participation. Therapists would be well advised to spend time and effort fostering this in order that the health benefits can be achieved.

5.4 BEHAVIOUR SUPPORT

One of the areas in which communication is important, identified by both health professionals and people with MS was maintaining motivation during an exercise programme. Motivation relates to both overarching themes of acceptance and communication. The communication needed to motivate people will differ depending on their acceptance of the condition and physical abilities. Goal setting was mentioned by the majority of the health professionals, with a small number of people with MS also highlighting goal setting as a way they encouraged themselves to take up and continue with exercise. Goal setting also links to the stage of acceptance of a person with MS, as goals need to reflect a person accepting what is realistic for their future. Goal setting provides a channel of communication between the patient and the health professional. It has also been suggested that setting mutual goals increases motivation by identifying meaningful aspects of the patient's life, and offering choice (Soundy et al., 2016). The process of goal setting could also be associated with supporting self-efficacy through verbal persuasion of the person's ability to achieve a goal.

Mastery of a behaviour is another element which supports the development of self-efficacy (Bandura, 1997). Achievement of goals can assist with the development of self-efficacy, particularly where behaviour-related goals (such as sticking to a plan of three exercise sessions per week) are used. People with MS in the current study spoke of difficulties maintaining motivation both when exercising unsupervised at home, and also of experiencing difficulties with exercise which they did not wish to reflect on. Having behaviour-related goals would allow mastery experience to be achieved on a daily or weekly basis even during periods when progress towards the longer-term functional outcome was slower. Health professionals also stated that they wished to give positive feedback, even when patients were not progressing as they wished to. This would also be possible using behaviour-related goals, and could assist in maintaining motivation. Longer-term outcome-focused goals such as independent walking can then be developed from the behaviour-related goals (Casey et al., 2018b). Patient-led behaviour-related physiotherapy goals have been associated with successful interventions to increase physical activity in people with osteoarthritis (Willett et al., 2019), suggesting this could be a suitable approach to support exercise for people with MS.

The need for self-efficacy, and for this to be appropriately facilitated at all stages of behaviour change is recognised in the Health Action Process Approach (HAPA), a model of behaviour change for chronic illness which has been advocated for use in MS (Schuler et al., 2019). In the current study some of the health professionals showed awareness of the need for supporting self-efficacy in people with MS taking up exercise. People with MS also spoke of fears related to not performing exercises effectively or exercising the wrong muscles and causing harm, showing a need to develop task-related self-efficacy (Schwarzer et al., 2011). There is increasing recognition that behaviour change support should be included at all stages of both physical activity and exercise interventions for people with MS (Motl et al., 2019a). Goal setting, as mentioned previously was identified by both health professionals and people with MS as a way to support exercise, is also included in the HAPA, where personal goals are referred to as intentions (Schwarzer, 2008). However it is acknowledged that a gap may exist between the formation of goals and the actions needed to achieve the goals (Schwarzer et al., 2011). This goal-action gap was evident in the current data from people with MS, a number of whom discussed their actions not living up to their good intentions to exercise at home. In order to address the goal-action gap, action planning (specifying when, where and how the exercise will take place), and coping planning (planning for when other factors, such as unpredictable MS symptoms, may impede the performance of exercise) are advocated by Schuler et al., (2019). Data from the people with MS, described symptom-related barriers leading to periods where they were unable to exercise. In order for an exercise programme to be successful, specific planning support from health professionals would be needed during these times. The inclusion of self-efficacy within the HAPA also relates to the overarching theme of acceptance, with different types of self-efficacy being required depending on a person’s stage of acceptance. For example, those who have accepted the physical limitations of their condition may have strong task-related self-efficacy to perform exercise, in order to improve their functional abilities, and manage their symptoms in the long-term. However, these people may need support for “recovery self-efficacy”, regaining control of their exercise programme following a health related setback (Schwarzer et al 2011). Awareness of these differing needs was not mentioned by the health professionals who participated in the current study, but could be a key part of the support offered over the course of an exercise programme when symptoms are likely to fluctuate. Questionnaires exist to assess exercise goal setting and planning (Rovniak et al., 2002) as well as self-efficacy in relation to exercise (McAuley, 1993). Both of these tools have been previously used in MS (Coote et al., 2017) and could be a measurable way to show how participants acquire skills in both elements of the HAPA. As well as measurement there is a need for clear strategies to support the development of self-efficacy and goal setting skills.

Different support needs of people with MS at different times was also highlighted by Learmonth et al. (2017a), who compared the needs of people with MS with varying levels of habitual physical activity. Those who were classed as ‘insufficiently active’ described needing greater input from health professionals in developing skills to prioritise exercise and alleviating worries about exercise safety as well as social accountability through organised one to one meetings. Insufficiently active people with MS also discussed the value of goal setting and planning (Learmonth et al., 2017a). In the current study participants who regularly exercised spoke of observing others with MS successfully completing a task, as inspiration towards being able to carry out the action themselves, suggesting the development of self-efficacy through vicarious experience. Similarly, more active participants in the study by Learmonth et al. (2017) were less likely to depend on their health professional for exercise advice, with some also wishing to promote exercise to other people with MS. This suggests these people were more accepting of their condition and limitations. This also suggests that the role of health professionals would be different at this stage of acceptance, with communication being adapted to suit the acceptance of the person with MS.

There is growing recognition of the need for health professionals to develop skills in supporting behaviour change, with a recent paper suggesting an example of a competency framework for smoking cessation (Dixon and Johnston, 2020). However knowledge and use of behaviour change techniques, particularly by physiotherapists who made up the majority of the participants in the focus groups appears to be limited. With no specific requirement for psychology education in undergraduate physiotherapy courses (Physiotherapy, 2020), the psychological content in student teaching is variable with less than a quarter of institutions questioned having named modules in psychology (Heaney et al., 2012). A review study in musculoskeletal practice showed that although they understood the value of behaviour change interventions, qualified physiotherapists felt that their training was not sufficient to enable them to use a wide range of these interventions (Alexanders et al., 2015). This suggests that better awareness of the principles of behaviour change, and the use of a more structured behaviour change approach on the part of health professionals could help people with MS feel more in control both of exercise programmes and longer-term functional goals. Education specific to the principles of behaviour change as a mandatory part of all healthcare courses could form a part of this.

5.5 SOCIAL SUPPORT FROM PEERS AND OTHERS

Getting going and keeping going" one of the themes from the data of the people with MS, showed a number of participants identified difficulties motivating themselves to exercise independently, with exercise groups viewed as a positive way to maintain motivation. In line with this, review studies have shown social support to be the behaviour change technique most used in both routine physiotherapy practice and in interventions to increase exercise adherence (Kunstler et al., 2017, Peek et al., 2016). As well as the role of health professionals to support exercise, the value of family and carer support was highlighted by both patients and health professionals. Both the focus groups and interviews with people with MS and health professionals, included discussion of MS-specific exercise groups. People with MS were broadly positive about being part of a group both for the development of peer support networks, and for exercise, as covered in the theme "A very accepting atmosphere". Participants spoke of being inspired by watching others perform functional tasks and even enjoying some healthy competition during exercises. The role of this vicarious experience appears to assist with the development of self-efficacy with the importance of MS role models has been highlighted previously (Learmonth and Motl, 2016) . Acceptance of one's condition is likely to be a factor here, which was observed to vary according to the individual. Some participants with MS stated they would much prefer to exercise in a mainstream class for as long as they could, or were put off from joining MS groups, which they felt did not reflect them. Health professionals also suggested consideration to the needs of the individual when group exercise or other group support is promoted to people with MS in order to ensure motivation is maintained. Participants of a study by Dennison et al. (2010), who were all in the early stages following MS diagnosis, also discussed negative aspects of joining an MS group. Some people felt that they were not disabled enough and did not belong there or that joining such a group could lead to their life becoming overly focused around their MS (Dennison et al., 2010).

In the current study, people with MS referred to friends and family members who helped with motivation and assistance to exercise. Within the HAPA, the importance of social support as a resource to help the initiation and continuation of health behaviour change is highlighted (Schwarzer et al 2011). These authors deemed "informational" social support (which could consist of health professionals demonstrating how to perform exercises) necessary along with "emotional" social support (in which carers or family members exercise along with participants). Health professionals who participated in the current study also felt the supportive role of carers was a key one, and that there was a need for them to be educated about the value and practicalities of exercise. However previous work has highlighted fears from carers about how best to support and encourage suitable exercise (Learmonth et al., 2020). Studies in other clinical populations such as stroke and cardiac failure have aimed to address this by providing carers with training and education about assisting their family member to exercise (Greaves et al., 2016, Vloothuis et al., 2018). The needs of those without family or friendship support networks were not mentioned by either the people with MS or the health professionals. Perhaps this should be a consideration in the design of future exercise initiatives for people with MS, as some participants may not have people at home to provide emotional and practical help. Health professionals may also need to consider other ways that they can offer ongoing support, or encourage this among group participants. Previous research has suggested developing online social media networks as a way to improve the behaviour change support offered by health professionals as part of exercise programmes (Dlugonski et al., 2012). This could foster remote peer support among people with MS, a method which has been advocated in work investigating the use of web-based resources by people with MS (Sweet et al., 2013). This is an example of individualised communication being used to enhance a person's experience of exercise, as identified by the health professionals in chapter 4 of this study. In summary, to assist in improving outcomes from exercise programmes, consideration should be given to the social circumstances and preferences of the person with MS.

5.6 CONCLUSION

The need for individualised support in relation to exercise has been highlighted from the work with both people with MS and health professionals. Communication and the building of a strong therapeutic relationship should be a focus from the very first meeting of patient and therapist, as this relationship is key to all future interactions to encourage shared decision making, and support self-efficacy. These focus groups have shown an evident need for health professionals to develop their knowledge and application of behaviour change techniques. Goal setting is most often used at the start of an intervention, but could be used more effectively to focus on exercise behaviour as well as outcome. A person's self-efficacy and ability to set goals could also be measured at each stage. Education for health professionals around these aspects of behaviour change support could strengthen this. Input should be adapted according to the person's activity level, acceptance of their condition, and individual preferences. This could include support for both action planning and coping planning in order that strategies are in place to deal with difficulties relating to exercise. The development of peer support networks as part of exercise interventions for people with MS could be another way for health professionals to encourage participation and the achievement of health benefits.

CHAPTER 6: ASSOCIATIONS BETWEEN PHYSICAL ACTIVITY, SEDENTARY BEHAVIOUR, AND MEASURES OF FUNCTION AND WELLBEING IN PEOPLE WITH MS

ABSTRACT

Background: Physical activity has been reported to have benefits for both psychological and physical function in people with multiple sclerosis (MS). Behaviours such as physical activity and sedentary behaviour, as well as physical function can be measured using both subjective and objective measures. However, few studies have assessed the associations between these behaviours and psychological and physical function using both subjective and objective measures.

Objective: To explore associations between the primary outcomes of physical activity and sedentary behaviour with secondary outcomes measuring psychological and physical function using both subjective and objective measures in people with MS.

Methods: People with MS (n=30, 24 female and 6 male) took part in an assessment of objective and self-reported physical activity and sedentary behaviour as well as measures of function and wellbeing. These included both device-measured and questionnaire measured physical activity and sedentary behaviour, walking ability measured by the Timed Up and Go, 25ft walking test and MS walking scale questionnaire. Aerobic fitness was measured using a submaximal exercise test and functional balance by the Berg Balance scale. Wellbeing was measured using the Fatigue Severity Scale, Hospital Anxiety and Depression Scale, and scores for pain and Subjective Vitality. Associations were explored using Spearman correlational analyses.

Results: Participants' mean age was 50.0 (±10.2) years, and mean Patient Determined Disease Steps score was 3.5 (± 2.2). Those with higher levels of moderate/vigorous physical activity (MVPA) and more daily steps, had better balance, faster walking speed, and a better self-reported assessment of walking ability. Less time spent in MVPA, fewer daily steps and more sitting was related to more severe MS disability. More physical activity and lower levels of sedentary behaviour were also associated with better scores for mental health outcomes. Those who were more sedentary had a slower walking speed. Differences in associations between self-reported and objectively measured outcomes with other outcomes were noted. For example, more objectively measured, but not subjectively measured sedentary behaviour was associated with higher depression. Greater total self-reported but not objectively measured physical activity was associated with a higher predicted maximum workload on the submaximal test.

Conclusions: There is a need to consider using both objective and subjective assessments when measuring physical activity and function in people with MS, as they could reflect different aspects of

activity or function. Objective assessments may not reflect the perceived effort required for a functional activity, which is incorporated in subjective measures.

6.1 INTRODUCTION

Multiple sclerosis (MS) is a chronic inflammatory neurological disease with a range of symptoms, such as muscle spasms and weakness, fatigue, ataxia, and visual problems (Dobson and Giovannoni, 2019). MS is symptoms frequently begin at a relatively young age, i.e., between 20-40 years, (Ford, 2020) which means that people live with its' impact for many years of their lives. In addition to physical symptoms, people with MS also experience psychological problems more frequently than the general population. For example, anxiety has been shown to be prevalent in 21.9% and depression in 23.7% of people with MS (Marrie et al., 2015b). The symptoms of MS have wide ranging effects on daily activities and employment. Given that there is no cure for MS, treatment of MS is focussed on reducing the symptoms. Exercise has been recommended as a way to manage MS symptoms, with meta-analyses showing improvements in strength, aerobic fitness, and mobility from exercise training programmes (Latimer-Cheung et al., 2013b, Platta et al., 2016b), depression (Herring et al., 2017), and fatigue (Pilutti et al., 2013b).

6.1.1 PHYSICAL ACTIVITY IN MS

Physical activity can be accumulated during activities at home, work, transport or leisure, can include lifestyle behaviours or purposeful exercise, and can be carried out at different intensity levels. Slow walking is classed as light intensity, brisk walking or gentle cycling is moderate intensity, running and team sports such as football are vigorous intensity physical activity. The benefits of regular physical activity for cardiovascular and metabolic health have been well documented in the general population (Warburton and Bredin, 2017), and physical activity has been related to higher aerobic fitness levels (Baumann et al., 2020). However, the majority of people with MS have lower levels of physical activity compared to the general population (Klaren et al., 2013, Kinnett-Hopkins et al., 2017a), as well as lower aerobic fitness (Langeskov-Christensen et al., 2015), particularly those who are older and have higher levels of MS disability (Motl et al., 2006, Langeskov-Christensen et al., 2015). There is evidence that higher levels of physical activity, even light intensity, are linked to greater aerobic fitness in MS (Motl et al., 2017c). Both increasing physical activity and aerobic exercise training have been linked to health benefits in MS, such as a reduced risk of cardiovascular events (Langeskov-Christensen et al., 2015) and improvements in fatigue, depression, anxiety, and pain (Pilutti et al., 2013a).

6.1.2 SEDENTARY BEHAVIOUR IN MS

It is not just physical activity which has been related to health outcomes, sitting time has also been investigated in people with MS. In the general population, sedentary behaviour has been shown to be associated with greater risk of mortality and morbidity (Katzmarzyk et al., 2019, Biswas et al., 2015). In people with MS, studies have reported between seven and ten hours of device-measured sedentary time per day (Motl et al., 2019b, Ezeugwu et al., 2015a, Veldhuijzen van Zanten et al., 2016a), and sitting time has been reported to be higher compared to healthy control participants (Sasaki et al., 2018b). Greater objective sedentary time in MS has been associated with older age, longer disease duration, and higher disability (Jeng et al., 2019), and higher self-reported sitting time with greater ambulatory impairment (Hubbard et al., 2015).

6.1.3 MENTAL HEALTH IN MS

There is evidence for people with MS experiencing higher levels of mental health problems compared to the general population (Marrie et al., 2015b). Tallner et al. (2015) reported that higher lifestyle physical activity in people with MS was associated with higher health-related quality of life. A three-week physical activity programme in people with MS significantly improved depression, fatigue, and sleep (Bahmani et al., 2019). In the general population, cross-sectional associations have been reported between sitting behaviour, depression (Zhai et al., 2014) and anxiety (Allen et al., 2019). However, to our knowledge, little research has looked into the effects of sedentary behaviour on wellbeing measures in MS. Possible links between amount of sedentary behaviour and anxiety and depression in MS could be further explored.

Subjective vitality reflects positive wellbeing. Previous work has shown that participating in a regular exercise programme has beneficial effects on vitality in the general population (Shepherd et al., 2015). In people with chronic pain, higher vitality is linked to better functional ability, fewer physical symptoms, and feelings of self-motivation and self-esteem (Ryan and Frederick, 1997). In MS less attention has been paid to positive wellbeing, with little known about possible associations between vitality and physical activity and sedentary behaviour.

6.1.4 FATIGUE IN MS

A survey of people with MS found fatigue to be one of the most common symptoms, experienced at least twice weekly by 76% of participants (Larocca, 2011). Fatigue is often reported to be the most debilitating symptom of MS (Hadjimichael et al., 2008). Both physical activity programmes (Pilutti et al., 2013a) and structured exercise training (Pilutti et al., 2013b) have been shown to improve fatigue in people with MS. Greater fatigue is associated with lower overall daily physical activity and higher sedentary behaviour in people with MS (Blikman et al., 2015). Those with greater fatigue were also observed to spend less time in moderate physical activity (Cavanaugh et al., 2011). Neither of these studies assessed self-reported physical activity, which has been shown to be overestimated compared to objectively measured physical activity in the general population (Dyrstad et al., 2013).

6.1.5 FUNCTIONAL ABILITY IN MS

The symptoms of MS can affect functions such as walking, balance, and independence with daily tasks. Those with ambulatory limitations due to MS accumulate significantly fewer daily steps, shorter bouts of activity and more daily time being inactive than those without ambulatory limitations (Cavanaugh et al., 2011). Higher levels of physical activity have also been linked to greater leg strength and quicker completion of a sit to stand task (Proessl et al., 2018). In general, more physical activity is associated with better physical function in MS. For example, a review revealed those taking part in more lifestyle physical activity had a higher functional level and less restriction to daily activities (Streber et al., 2016). The majority of reviewed studies recruited participants with mild to moderate levels of disability. It would therefore be useful to have more detailed information about the associations between physical activity and functional ability in people with MS across a broader spectrum of disability. Interestingly less than a fifth of the studies included in the review, included assessments of both objectively and subjectively assessed physical activity and functional ability (Streber et al., 2016). Other work has shown different associations between subjective and objective assessments of walking and other MS parameters. Kalron (2016) found that higher fatigue in people with MS was related to lower self-reported walking ability but not to objectively measured gait parameters. Similarly, in a review of interventions targeting an increase in physical activity in people with MS, those employing only subjective measures of physical activity found significant improvements, whereas the results of the interventions using objective measures of physical activity reported less consistent change in the amount of physical activity post-intervention (Coulter et al., 2020).

6.1.6 OUTCOME MEASUREMENT IN MS

As has been highlighted, studies exploring activity and symptoms in MS have employed varied methods of assessment, frequently including only either subjective or objective measures. Many studies use the International Physical Activity Questionnaire (IPAQ), which has a single question to assess sedentary behaviour. However, the IPAQ was perceived less favourably than other sedentary behaviour questionnaires among a sample of people with MS (Hensman et al., 2019). The importance of assessing sitting in a range of environments including the workplace, transport, and leisure has been identified (Owen et al., 2010). Sasaki et al. (2018c) found people with MS using the Marshall sitting questionnaire overestimated their sedentary behaviour by a mean of 2.65 hours per day compared to objective assessment. Similarly, self-reported physical activity can be inaccurate with research showing an underestimation of daily walking and an overestimation of vigorous activity compared to accelerometer data (Dyrstad et al., 2013). It would therefore be useful to collect both objective data, to quantify amounts, intensities, and patterns of activity, and subjective information giving more detail on the specific activities making up a person’s day.

Other difficulties associated with solely using self-report measures of activity are differences in energy expenditure between people with MS and healthy controls. For example a significantly greater energy cost per step was found in people with both mild (Franceschini et al., 2010) and higher disability than controls during walking (Coote and O'Dwyer, 2014). This suggests that everyday functional activities may be perceived as more intensive in people with MS. In line with this, perceptions of higher fatigue can be related to self-reported but not objectively measured gait difficulties (Kalron, 2016). There are therefore differences in peoples’ perceptions of their physical ability and objectively measured assessments. Having both types of data allows for greater clarity in finding associations between different parameters.

6.1.7 AIM OF THIS STUDY

The primary outcome of this study was physical activity, measured both subjectively and objectively in a group of people with MS with a range of disability. The secondary outcomes were balance, walking mobility, cardiovascular fitness and muscle strength, as well as measures of mental wellbeing which included subjective vitality, depression and fatigue. The overall aim of the study was to explore associations between the primary outcomes of physical activity and sedentary behaviour with these other aspects of physical and mental health.

6.2 METHODS

6.2.1 PARTICIPANTS

Thirty participants were recruited from consultant and nurse-led MS clinics at the Dudley Group NHS Foundation Trust. Participants were recruited for a twelve-week home-based exercise programme designed for people with MS involving short twice weekly sessions of balance, strength exercises and walking, tailored to the individual's ability. The inclusion criteria were: a consultant confirmed diagnosis of MS, being ambulatory, with an Expanded Disease Severity Scale (EDSS) score of up to 6.5, and having home internet access. Participants were excluded if they were pregnant, had any co-existing cardiovascular disease or other factors preventing safe participation in exercise or had experienced a relapse or any change to symptomatic or disease modifying medication within the last 30 days. Those who were currently participating in regular structured exercise programmes or having ongoing physiotherapy were also excluded. Ethical approval was provided by South Birmingham Ethics Committee and all participants provided written informed consent prior to participating.

6.2.2 PROCEDURES

The current chapter is a cross-sectional study and will report the baseline data of the participants. Participants attended two assessment visits. They were asked to avoid any strenuous activity for 24 hours prior to each visit and to refrain from a heavy meal, caffeine or smoking within two hours. They were also advised not to attend the exercise test if they had been unwell with an infection in the preceding week. During visit 1 (lasting approximately 90 minutes), the following assessments were taken: Timed 25ft walk, Berg Balance Scale, Timed Up and Go, Grip Strength, Submaximal Fitness test. At the end of the visit, participants were provided with an accelerometer to wear for the next 7 days. They were also given a questionnaire pack to complete at home, which included a demographic questionnaire as well as measures of wellbeing. Visit 2, which took place on average 12.0 (SD = 7.8) days following visit 1, lasted approximately one hour. During visit 2 participants returned the accelerometer and were asked to complete questionnaires relating to their sedentary behaviour and physical activity over the preceding week. After this, participants were asked to complete tests of lower limb muscle strength.

6.2.3 MEASURES

PERCEIVED MS SEVERITY

Patient Determined Disease Steps (PDDS) (Hohol et al., 1995)

This questionnaire has been specifically developed for people with MS and assesses perceived disease severity based on the walking ability of the individual. Participants were asked to rate severity of their disease on a scale from 0 (mild symptoms with activity not limited) to 8 (unable to sit in a wheelchair for more than one hour, mainly bedridden). PDDS scores correlate strongly with the neurologist administered Expanded Disability Status Scale (Learmonth et al., 2013d).

PHYSICAL ACTIVITY AND FITNESS

Activity monitoring using accelerometer device

Participants were asked to wear an accelerometer (Actigraph GT3X) for seven days on the right hip to measure their physical activity. They were instructed to wear the small non-invasive device during all waking hours, apart from during any water-based activities. Participants completed a log sheet during the wear period which indicated the days and times that the accelerometer was worn. An interval of 60 or more consecutive minutes of zero activity counts was classed as non-wear with allowance made for 1-2 min of counts between 0 and 100. Subtracting non-wear from 24 hours for each day gave the total wear time (Troiano et al., 2008). Based on the records of the participants, time parameters of 7am until 11pm were set for a waking day with a minimum of ten hours total wear time considered a valid day (Klaren et al., 2013). Those with four or more valid days including at least one weekend day were included in the analysis. The standard cut point of below 100 counts per minute was used for sedentary behaviour. For the analysis of accelerometer data, MS specific cut points were used which are 100 – 1722 counts per minute Light Intensity Physical Activity (LIPA), and 1723 or more counts Moderate/Vigorous Physical Activity (MVPA) (Sandroff et al., 2012, Sasaki et al., 2017).

Godin Leisure Time Exercise Questionnaire (GLTQ) (Godin and Shephard, 1985)

This questionnaire measures usual weekly physical activity. Participants are asked to indicate the frequency of mild, moderate, and strenuous exercise during the last seven days. A quantity of total leisure activity is calculated by multiplying the weekly frequencies by metabolic equivalents (e.g., mild exercise = x 3, moderate exercise = x 6, and strenuous exercise = x 9) and adding them together. This total score can be interpreted as insufficiently active (less than 14 units), moderately active (14 – 23 units) or active (24 units or more). Using this scoring method, the GLTQ has shown sensitivity in detecting predictable differences in activity levels between people with MS and healthy controls

(Sikes et al., 2019). Test-retest reliability over six months was good (ICC=.74) (Motl et al., 2014). The questionnaire is valid against pedometer values and scores on the International Physical Activity Questionnaire in people with MS (Sikes et al., 2019) and has been widely used in MS research (Motl et al., 2006, Thomas et al., 2017).

SEDENTARY BEHAVIOUR

Sedentary Behaviour Questionnaire (SBQ) (Rosenberg et al., 2010)

This questionnaire measures sedentary behaviour. Participants were asked to indicate the amount of time spent on nine sedentary behaviours: watching television, playing computer/video games, listening to music, talking on the phone, doing paperwork or office work, reading, playing a musical instrument, doing arts and crafts and sitting driving/riding in a car bus or train. Participants answered for weekdays and weekend days using a grid with nine options ranging from "none" to "6 hours or more". The total time spent on all nine behaviours makes up daily sedentary time. Partial correlations between sedentary time assessed by accelerometer and with this questionnaire, were low overall (highest r = .26) in women with no significant correlations in men (Rosenberg et al., 2010). In adults (mean age = 20), test-retest reliability was higher for weekdays, intraclass correlation (ICC) = 0.64 - 0.9 than weekends (ICC = .51 – .93)(Rosenberg et al., 2010). This questionnaire has been previously used in MS where it was viewed as the favourite of six different sedentary behaviour questionnaires (Hensman et al., 2019).

PSYCHOLOGICAL WELLBEING

Subjective vitality scale (SVS) (Ryan and Frederick, 1997)

This is a six-item questionnaire measuring a person's feelings of energy and alertness in the past two weeks, by indicating how much they agree with a series of statements e.g. 'I have been feeling energised'. The questionnaire is scored on a seven-point scale from 1 'Not at all true' to 7 'Very true'. This scale has been previously used in MS (Dawes et al., 2014). In people with rheumatoid arthritis, the measure has good internal consistency ($\alpha = .93$, $\rho = .92$) and significant correlations ($p < .05$) with fatigue, anxiety, and depression (Rouse et al., 2015).

Hospital Anxiety and Depression Status scale (HADS) (Zigmond and Snaith, 1983)

This questionnaire measures anxiety and depression over the preceding two weeks using two subscales containing seven items each. Participants respond to statements e.g.: "I feel tense or 'wound up" (Anxiety subscale) or "I feel cheerful" (Depression subscale), using descriptors on a four-point scale, e.g.: 'Not at all', 'Not often', 'Sometimes', 'Most of the time'. Descriptors are phrased differently according to the question. Higher levels of anxiety and/or depression are indicated by higher scores. Many studies of people with MS have used this questionnaire (Litster et al., 2016). Test-retest reliability is good, ICC=.83 for both anxiety and depression subscales (Marrie et al., 2018). The HADS has shown good criterion validity (Honarmand and Feinstein, 2009) and good construct validity against other similar measures for people with MS (Litster et al., 2016). The assessment of depression using HADS is independent of fatigue, unlike some measures, which has led to it being suggested as a useful measure for MS (Bol et al., 2009).

Multiple Sclerosis Impact Scale (MSIS) (Hobart et al., 2001)

This 29-item questionnaire measures the perceived impact of a participant's MS over the preceding two-week period. Twenty items refer to physical aspects (e.g. 'Spasms in your limbs') and nine to the psychological impact (e.g. 'Problems concentrating). Each item is rated on a scale ranging from 1 'not affected at all' to 5 'extremely affected'. Subsequently, an overall percentage of the possible total is calculated for the physical impact of MS and psychological impact of MS, respectively. This commonly used questionnaire has been shown to be a valid and reliable measure of both physical and psychological constructs in MS (Riazi et al., 2002).

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

This questionnaire consists of nine statements about the impact of fatigue on a person's daily life, e.g. 'Fatigue interferes with my work, family or social life'. Participants are asked to rate each on a seven-point scale from 1 'Strongly disagree' to 7 'Strongly agree', with the overall score being a mean value of all responses. The scale showed moderate test-retest reliability and good construct validity when measured against the longer Modified Fatigue Impact Scale (Learmonth et al., 2013e). This measure is widely used in MS and was employed in seven out of seventeen studies, in a meta-analysis on the impact of exercise on fatigue in MS (Pilutti et al., 2013b).

Visual Analogue Scales for Fatigue and Pain (Kersten et al., 2012)

These are horizontal lines 100mm long with the statement "No fatigue/pain" at one end and "Worst possible fatigue/pain" at the other. Participants are asked to mark an X on a line to describe either their amount of pain or fatigue in the past two weeks. This is done separately for pain and for fatigue. Visual analogue pain scales have been commonly used in research over many years (Kersten et al., 2012). Their use in MS includes assessing the impact of a hydrotherapy exercise intervention on pain (Castro-Sanchez et al., 2012). Visual analogue fatigue scales are quick to administer and have been used in a number of MS studies (Elbers et al., 2012).

FUNCTIONAL ABILITY

Berg Balance Scale (Berg et al., 1989)

This is an assessment of functional balance. Participants were asked to complete fourteen everyday tasks which can challenge balance e.g. turning to look behind or picking up an item from the floor. Participants were asked to attempt each task, which is scored by the observing researcher from 0 (unable) to 4 (fully independent). The final score was the sum of all measures (maximum 56). The scale has shown high ratings of test-retest (ICC=.92) and inter-rater reliability (ICC=.97) in people with a range of neurological conditions including MS (Godi et al., 2013). The scale also has excellent correlations with other clinical balance measures showing high construct validity (Blum and Korner-Bitensky, 2008). This measure has been widely used in MS (Gunn et al., 2015).

Timed up and go test (TUG) (Podsiadlo and Richardson, 1991)

This is an assessment of functional gait which incorporates going from sit to stand, walking, and turning. Participants began this test sitting in a chair with arms. Participants were asked to, on the word “Go”, stand, walk three metres at their usual pace, turn around and return to the starting position. The use of walking aids is allowed if normally required, and these were placed within reach at the start of the test. Time taken to complete this is recorded as the outcome of the test. The TUG has been used in many studies in MS (Learmonth et al., 2014, Thomas et al., 2017). Construct validity is good with high correlations (Spearman ρ = .71 - .9) found between the TUG and other measures of ambulation in people with MS (Sebastião et al., 2016). A significant but weaker correlation (Spearman ρ = .47) was also found between the TUG and the MS Walking Scale 12 questionnaire (Kalron et al., 2017).

Timed 25ft walk test (Motl et al., 2017a)

This is an assessment of walking speed. A 25ft *(*7.62 metre) walkway was pre-measured and marked. Participants were asked to walk at their normal comfortable speed with a standing start and finish. The instructions were given: “I will say ready, set, go. When I say go, walk as quickly and safely as you can until I say stop”. Two tests were carried out with the mean time calculated. This test has shown high test-retest reliability (ICC’s > .9) across both short and longer periods (Motl et al., 2017a). It has also correlated strongly with subjective and objective measures of gait in MS (Motl et al., 2017a, Learmonth et al., 2014).

MS Walking Scale (MSWS-12) (Hobart and Riazi, 2003)

This questionnaire measures self-reported difficulty with walking, based on twelve questions. Participants are asked to indicate how much their walking has been affected. More specifically, "In the past two weeks how much has your MS…?" e.g. "Slowed down your walking". Each item is rated on a scale from 1 'Not at all' to 5 'Extremely'. Overall scores are converted to a percentage with higher scores showing greater impact of a person's MS on walking. The MSWS-12 has been used widely in MS research. Test-retest reliability over a six-month period was strong (ICC = .927) with the measure showing better precision and a smaller clinically important change score in those with a higher disability level (Learmonth et al., 2013a). The MSWS-12 has also shown strong correlations with objective measures of disability including the timed 25ft walk and TUG ($p<.001$) (Goldman et al., 2017).

Submaximal fitness test (Adapted from Golding, Meyers et al 1989)

This test is a measure of aerobic fitness and involved cycling on a Keiser M3 Indoor cycle ergometer at gradually increasing three-minute workloads based on the YMCA submaximal test protocol (Golding et al., 1989). A similar protocol for people with MS was published by Gappmaier (2012), who advocated the value of submaximal exercise testing. The requirement for proficient testers and advanced equipment, as well as greater risk of complications during maximal exercise testing, where participants exercise to exhaustion, means that submaximal testing offers a safer option for those with chronic illness (Gappmaier 2012). Throughout the assessment, heart rate was measured using a chest-worn heart rate monitor (Polar T31, UK). Pre- and post-exercise blood pressure were measured from the upper left arm using an Omron M2 blood pressure monitor. Participants completed a three-minute warm-up at 20 watts workload to familiarise themselves with the task. The first workload from 3-6 minutes was also at 20 watts. Heart rate was recorded at the end of minute 5 and minute 6 of exercise. If the two heart rate values were not within 5 beats per minute (defined as steady state), the participants continued cycling for another minute. The heart rate was then recorded at 7 minutes. Once steady state had been achieved the workload was increased by 20 watts. This was repeated for a maximum of three additional workloads. The maximum total time for the test was 15-18 minutes. Participants were asked to maintain consistent revolutions per minute (RPM) of 50-60 throughout the assessment. The test was stopped when the participant had completed two workloads with heart rate between 110 beats per minute and 75% of age-predicted heart rate maximum or immediately if they stated they were unable to continue. Heart rate and Rated Perceived Exertion (RPE) using the 20-point Borg scale (Borg, 1982) were measured in the last 15 seconds of each stage. On termination of the test, participants carried out a three-minute cooldown on the cycle ergometer pedalling at their own preferred speed with gradually decreasing workloads. They then sat quietly to allow heart rate and blood pressure to return to the pre-exercise state and were given water to drink. Steady-state heart rate at each workload allowed calculation of a predicted maximum workload for each participant. First the regression of HR and workload was conducted, and subsequently, the predicted workload at the maximum predicted heart rate (calculated as 220 – age) was calculated based on the regression equation (Akalan et al., 2008).

Grip strength of the dominant hand

This was measured using the Camry digital hand dynamometer with the participant seated upright, the shoulder in a neutral position, elbow flexed to 90° and forearm in mid-prone position. The researcher took the weight of the dynamometer and adjusted the grasp to fit the participant's hand. The instructions were given "I will ask you to squeeze this hand grip as hard as you can. You will take a breath in, then blow out while you squeeze." The equipment was demonstrated and the participant allowed to perform one practice trial. Three tests were done with the mean value calculated (Adapted from National Health and Nutritional Examination Survey, Muscle Strength Procedures Manual, 2011).

Lower limb muscle strength testing

Tests were carried out for muscle strength in left and right hamstrings, abductors, quadriceps, plantarflexors and dorsiflexors using the MicroFET 2 digital hand-held dynamometer which measures applied force in kilograms. For these tests participants were seated in a purposefully-made chair with hips and knees flexed to 90°. The chair allowed the dynamometer to be fixed in a range of positions to provide resistance to the desired muscle group. For each muscle group, the participant was instructed to "Push against the pad as hard as you can for as long as you can." The researcher took three readings for each muscle group, with a mean score being calculated and mean scores being reported for the left and right of each muscle group.

6.2.4 DATA REDUCTION AND ANALYSIS

Following entry into a database, the data were initially examined for normality and outliers. In fewer than 25% of cases the answer to a single question on a questionnaire had not been entered. A 'personal mean score' was used to calculate substitute values. These values used a mean of the individual participant's scores for non-missing items of the subscale (Peyre et al., 2011). Two missing data values for the SBQ were verified by referring to the participant's scores on a second sedentary behaviour questionnaire with similar items. All analyses were conducted using SPSS Statistics version 26 (SPSS Inc., Chicago, IL). Data are presented in text and tables as mean, with standard deviation, and range. A paired-samples t-test showed no significant differences between objectively measured LIPA or MVPA on weekdays and weekends. Therefore, a weighted mean overall value for LIPA and MVPA, respectively, was used for the analysis. Objectively measured weekday sedentary time was significantly higher than weekend sedentary time (p=.047), however the difference was marginal (32 minutes per day) therefore a weighted mean value was reported. A Wilcoxon signed ranks test for non-parametric data showed no significant differences between subjectively assessed weekday and weekend sedentary time. Non-parametric testing (Spearman's) was used to examine correlations between physical activity and sedentary behaviour with 1) PDDS and psychological wellbeing, and 2) objective and subjective measures of physical function.

6.3 RESULTS

6.3.1 PARTICIPANTS

Thirty people with MS (24 women and 6 men) participated in this study. Participant characteristics are displayed in Table 6.1. As is evident from the table, the majority of participants were female and white British or Irish. The sample included a range of ages from 28 – 65 years and PDDS scores ranged from 0-7.

Table 6.1. Participant demographic information

Outcome measure	Mean (SD)	Range
Age (years)	50.0 (10.2)	28-65
Female sex (N (%))	24 (80%)	
Time since diagnosis (years) **Unknown 6**	9.1 (6.3)	1-27
Married/cohabiting (N (%)	18 (60%)	
Ethnicity (N (%)		
White British or Irish	29 (96.7)	
Indian	1 (3.3)	
BMI (kg/m^2)	28.8 (7.5)	19.2 – 54.1
Disease Modifying Medications	9 (30%)	
PDDS	3.5 (2.2)	0-7

Note: BMI: Body Mass Index, PDDS: Patient Determined Disease Steps,

6.3.2 PHYSICAL ACTIVITY AND SEDENTARY BEHAVIOUR

Table 6.2 presents both objective and subjective measures of physical activity, and sedentary behaviour. There were substantial individual differences in sedentary behaviour and physical activity levels, assessed both objectively and subjectively.

Table 6.2. Baseline physical activity and sedentary behaviour

Physical activity and sedentary behaviour – Accelerometer data		
	Mean (SD)	**Range**
Overall LIPA (min/day)	76 (24)	33 - 131
Overall MVPA (min/day)	32 (20)	7 - 88
Overall sedentary time (min/day)	716 (74)	499 - 876
Overall sedentary time (%)	86.8 (4.9)	74.5 – 94.0
Overall LIPA (%)	9.2 (3.3)	4.0 – 19.5
Overall MVPA (%)	3.9 (2.5)	0.9 – 11.3
Overall steps per day	4016 (2188)	764 - 9064
Physical activity and sedentary behaviour – Self-report data		
GLTQ	13.8 (14.4)	0 - 51
SBQ – Overall SB (min/day)	549 (274)	171 - 1166

Note: LIPA: light intensity physical activity, MVPA: moderate/vigorous physical activity, GLTQ: Godin Leisure-Time Exercise Questionnaire, SBQ: Sedentary behaviour questionnaire, SB: Sedentary Behaviour

6.3.3 PSYCHOLOGICAL WELLBEING AND FUNCTIONAL MEASURES

Table 6.3 presents measures of psychological wellbeing for all participants. Table 6.4 presents functional measures including balance, gait, and submaximal fitness test and strength outcomes for all participants.

Table 6.3: Baseline psychological wellbeing data

Outcome measure	Mean (SD)	Range
Subjective Vitality	2.9 (1.4)	1.0 – 5.3
HADS Depression	8.0 (4.2)	1 - 17
HADS Anxiety	9.5 (4.5)	1 – 16
MSIS Physical Impact Scale	47.6 (23.7)	5.0 – 86.3
MSIS Psychological Impact Scale	45.2 (25.2)	2.8 – 88.9
Fatigue Severity Scale FSS-9	4.9 (1.7)	1.9 – 7.7
Visual Analogue Fatigue Scale	53.4 (26.7)	4 – 92
Visual Analogue Pain Scale	36.3 (24.7)	0 – 74

Table 6.4: Baseline functional ability data

Outcome measure	Mean (SD)		Range	
Walks unaided n (%)	17 (56.7)			
Berg Balance Scale	42.3 (10.7)		19 – 55	
Timed up and Go (s)	17.9 (13.8)		6.7 – 71.6	
Timed 25ft walk (s)	14.0 (9.8)		5.3 – 45.7	
MS Walking Scale	73.7 (25.6)		20 - 100	
Predicted maximum workload (watts)	157 (53)		39 – 287	
Grip Strength of dominant hand (kg)	21.0 (11.3)		5.7 – 54.8	
Muscle strength (kg)	**L**	**R**	**L**	**R**
Knee extensors	7.9 (4.7)	6.9 (5.2)	1.6 – 21.2	1.0 – 23.2
Knee flexors	3.7 (1.2)	3.2 (1.1)	1.1 – 5.7	1.0 – 4.5
Hip abductors	5.3 (3.6)	4.1 (2.8)	0.5 – 13.2	1.6 – 10.1
Plantarflexors	5.0 (3.2)	4.1 (2.4)	1.1 – 13.9	0.5 – 11.1
Dorsiflexors	4.9 (2.9)	4.1 (3.1)	0.4 – 10.3	0.5 – 13.1

6.3.4 ASSOCIATIONS BETWEEN ACTIVITY LEVELS, DISABILITY AND PSYCHOLOGICAL WELLBEING

Table 6.5 reports the correlation analyses between physical activity and sedentary behaviour with PDDS and measures of psychological wellbeing including fatigue. Spearman rank correlation analyses revealed that more severe disease activity (based on PDDS) was related to less time spent in MVPA, fewer daily steps, and more sitting. Those who reported higher levels of subjective vitality were less sedentary, engaged with more light intensity physical activity and more daily steps. A higher level of depression was related to more sedentary behaviour and fewer daily steps. No other significant correlations were found with either objective or subjective measures of physical activity and sedentary behaviour.

Table 6.5: Associations between physical activity/sedentary behaviour, PDDS and psychological wellbeing

	Objective				Subjective	
	LIPA % time	**MVPA % time**	**Steps**	**Sedentary behaviour (%)**	**Physical Activity (GLTQ Total)**	**Overall SB (SBQ)**
PDDS	-.28 p=.181	-.62 p=.001	-.60 p=.002	.48 p=.019	.42 p=.847	.25 p=.254
Subjective Vitality	.52 p=.010	.34 p=.109	.48 p=.017	-.47 p=.022	.19 p=.381	-.03 p=.886
HADS Depression	-.39 p=.053	-.35 p=.083	-.43 p=.027	.41 p=.037	-.40 p=.056	.28 p=.170
HADS Anxiety	-.02 p=.919	.21 p=.314	.06 p=.776	-.16 p=.433	-.34 p=.117	.03 p=.889
MSIS (Physical)	-.11 p=.614	-.30 p=.152	-.30 p=.152	.13 p=.554	-.05 p=.831	.08 p=.725
MSIS (Psychological)	-.26 p=.227	-.14 p=.502	-.15 p=.488	.21 p=.322	-.28 p=.189	.29 p=.184
Fatigue Severity Scale (FSS-9)	-.15 p=.510	-.07 p=.767	.12 p=.580	.01 p=.966	-.25 p=.259	.26 p=.239
Visual Analogue Fatigue Scale	-.16 p=.460	-.09 p=.676	-.11 p=.599	.05 p=.834	-.06 p=.802	.22 p=.306
Visual Analogue Pain Scale	-.39 p=.069	-.08 p=.732	-.19 p=.387	.17 p=.443	-.05 p=.814	.00 p=.988

6.3.5 ASSOCIATIONS BETWEEN ACTIVITY LEVELS AND PHYSICAL FUNCTION

Table 6.6 displays the associations between physical activity and sedentary behaviour with objective and subjective measures of physical function. These analyses revealed that those with higher levels of MVPA and more daily steps, had better balance, faster walking speed and a better self-reported assessment of walking ability. In addition, those who were more sedentary had a slower walking speed. A higher self-reported physical activity measured by the GLTQ was associated with a higher predicted maximum workload from the submaximal VO_2 test. No significant correlations were found with any other subjective measures of physical activity and sedentary behaviour. These analyses were also completed for measures of physical activity and sedentary behaviour in relation to strength of five lower limb muscle groups. This revealed no significant associations between lower limb strength and subjective or objective activity levels (data not reported).

Table 6.6: Associations between physical activity/sedentary behaviour and physical function

	Objective				Subjective	
	Sedentary behaviour (% time)	**LIPA (% time)**	**MVPA % time**	**Steps**	**Physical Activity (GLTQ)**	**Overall SB (SBQ)**
Berg Balance Scale	-.36 p=.076	.18 p=.394	.43 p=.022	.45 p=.005	.06 p=.788	.09 p=.654
Timed Up and Go	.47 p=.016	-.20 p=.339	-.65 p<.000	-.66 p<.000	-.18 p=.410	.09 p=.635
Timed 25ft Walk	.42 p=.037	-.16 p=.438	-.61 p=.001	-.66 p<.000	-.24 p=.278	.05 p=.810
MS Walking Scale (%)	.40 p=.051	-.16 p=.443	-.64 p=.001	-.57 p=.003	-.10 p=.644	.19 p=.376
Predicted maximum workload	.08 p=.733	-.30 p=.194	.14 p=.561	.20 p=.406	.54 p=.026	.21 p=.387
Grip Strength	.09 p=.674	-.27 p=.176	.09 p=.660	-.07 p=.741	-.03 p=.881	.10 p=.598

6.4 DISCUSSION

The primary outcomes of this study were physical activity and sedentary behaviour measured subjectively and objectively. Results show that this sample of people with MS with a range of disability levels demonstrated low levels of both light (LIPA) and moderate to vigorous intensity physical activity (MVPA), at 9.2% and 3.9% of the day, respectively. Participants also had high levels of sedentary behaviour, with a mean of 86.8% of the day spent sedentary. More disabled individuals did fewer daily steps, less MVPA, and sat for longer each day. In relation to the secondary outcomes related to functional ability better objectively measured balance, gait speed, and Timed Up and Go (TUG), as well as self-reported walking ability were associated with more MVPA and daily steps. Greater total self-reported physical activity was associated with better fitness measured by predicted maximum workload on the submaximal test. There were no associations between grip or lower limb strength and subjective or objective measures of physical activity or sedentary behaviour. For the wellbeing-related secondary outcomes, scores were generally low for vitality and high for both anxiety and depression. Being less sedentary, and engaging with more LIPA and more daily steps was associated with higher levels of subjective vitality. Similarly, those with higher depression scores were more sedentary and accumulated fewer daily steps. These associations were not found for subjective measures of activity.

6.4.1 MUSCLE STRENGTH AND ACTIVITY LEVEL

In the current study, physical activity and sedentary behaviour were not found to be associated with grip or isometric lower limb strength. Findings of a small number of studies show some associations between walking ability and the strength and endurance of lower limb muscle groups in MS (Güner et al., 2015, Mañago et al., 2018), however physical activity and sedentary behaviour measures in relation to strength of key muscle groups related to walking have received little attention in previous MS research, suggesting a need for further study. In line with previous findings (Cavanaugh et al., 2011, Blikman et al., 2015, Jeng et al., 2019), higher disability was associated with objectively measured lower MVPA, fewer steps, and more daily sitting time. However, PDDS was not significantly associated with self-reported activity or sitting. In addition, better scores on functional measures of disability (objective balance and walking speed) were associated with higher MVPA and steps, but not with self-reported activity measured by the GLTQ. Weikert et al. (2012) similarly found accelerometer data to be associated with objective mobility measures, but not with self-reported PA in people with MS. These authors highlighted the limitations of the GLTQ, which is phrased to capture structured periods of exercise, rather than physical activity more broadly. The current results showed higher GLTQ scores to be associated with better aerobic fitness, suggesting questionnaire data may better represent the activities of those who engage in periods of formal exercise. Lower objectively measured sedentary time was associated with faster walking (TUG and 25ft walk) as was found in previous work (Hubbard et al., 2015). Current results also showed faster gait to be associated with more MVPA and steps but not with self-reported physical activity or subjective walking ability measured by the MSWS-12. Better MSWS-12 scores were also associated with higher levels of MVPA and more steps. Consistently, in the current data, associations between both physical activity and sedentary behaviour and functional outcomes are different, depending on whether physical activity and sedentary behaviour are measured subjectively or objectively. Earlier work has shown that for people with MS, particularly those with significant disability, the energy cost of everyday activities is greater than for healthy people (Coote and O'Dwyer, 2014). This could mean that objectively lighter functional activity is being perceived as moderate intensity among the current sample, showing the value of using both self-report and objective measures in work of this kind.

6.4.2 WELLBEING MEASURES

The scores on the physical and psychological subscales of the Multiple Sclerosis Impact Scale (MSIS-29) showed similarly significant impact in both domains, but these were not related to either physical activity or sedentary behaviour. Although scores for pain were relatively low (36.3%), other aspects of psychological wellbeing were poor: subjective vitality was low (mean 2.9 out of 7), and both depression and anxiety were high in line with previous work (Marrie et al., 2015b). Measures of physical activity or sedentary behaviour were not associated with anxiety. More daily steps were associated with a lower score for depression, which reflects earlier work in which engaging in physical activity led to a later decrease in depressed mood (Kratz et al., 2019). These results suggest that doing more physical activity can have a positive effect on mood. More objective, but not subjective sedentary behaviour was associated with higher depression scores which may be reflective of the under-reporting of their sedentary behaviour by the current participants, which has been found previously (Prince et al., 2020). Two thirds of the current participants were not employed. Self-report sedentary behaviour data has been found to be more accurate when participants are asked to record sitting while at work compared to sitting in leisure time (Prince et al., 2020), which may help to explain this. Other work in MS has shown associations between subjective sedentary behaviour and depression (Marck et al., 2020). Their sample was both less sedentary by two hours per day, and more physically active than current participants, with 30% reporting taking part in regular vigorous exercise compared to 13% in the current sample. This suggests that overall activity levels may affect the associations between sedentary behaviour and mental health. Current results also showed higher subjective vitality was associated with taking part in more daily LIPA and steps, and being objectively less sedentary but not with self-reported measures of sedentary behaviour or physical activity. Previous work in the general population has also found significant improvements in vitality after participating in two different exercise programmes (Shepherd et al., 2015). The impact of exercise on vitality in MS therefore warrants further study.

6.4.3 FATIGUE

Mean Fatigue Severity Scale (FSS) scores of participants in the current study were 4.9/7, which shows relatively high MS-related fatigue (Krupp et al., 1989). There were no correlations between fatigue and either objective or subjective measures of physical activity and sedentary behaviour. This differs from previous work which has shown higher sedentary behaviour and lower overall physical activity to be associated with greater fatigue in MS (Blikman et al., 2015). Similarly, Neal et al. (2020) found a higher fatigued group (mean FSS ≥ 4.0) to spend more time sedentary and less time in LIPA and MVPA than a non-fatigued group (mean FSS ≤ 4.0). However, when controlling for group differences in PDDS, PA and SB were no longer different between the two groups (Neal et al., 2020). Franceschini et al. (2010) also found that walking speed in those with low levels of MS disability was associated with the level of disability but not with perceived fatigue. In the current study, severity of fatigue was not associated with disability level. In a group with similar fatigue severity (5.4), Blikman et al. (2018) found weak associations between objective physical activity and sedentary behaviour and physical fatigue only. Similarly to the current results, activity measures were not associated with either FSS score, cognitive or psychosocial fatigue. As the FSS focuses mainly on the severity of physical fatigue, it may be that this has less of an impact on current participants than the cognitive and psychosocial aspects.

6.4.4 FITNESS LEVEL

Objectively measured physical activity was not associated with fitness level in the current study, but associations were reported between self-reported physical activity and fitness. These findings differ from those of Motl et al (2017d) who found VO_2 peak to be significantly correlated with MVPA and LIPA in a sample with a median PDDS of 4.0, similar to the current study population. The lack of correlation in the current results may be related to differences in aerobic fitness test outcomes using different testing protocols. Equipment used, duration of the test, and watt increase can all affect results (Langeskov-Christensen et al., 2015). In the current study a submaximal rather than a maximal test was used. Kuspinar et al. (2010) found that results of a submaximal exercise test were predictive of VO_2 peak using cycle ergometry in people with MS, endorsing the value of using submaximal testing in this population who may have difficulty completing maximal exercise tests. However, the step test used by Kuspinar and colleagues, requires better balance and may be less suitable for people with MS than cycle ergometry. Nevertheless, not all current participants were able to attempt the cycle ergometer test due to either their disability preventing safe sitting on the cycle ergometer, or exceeding the weight limitations of the equipment. There may therefore be a need for alternative methods of measuring fitness in MS, which could include upper body testing (Langeskov-Christensen et al., 2015).

6.4.5 SEDENTARY BEHAVIOUR

In the general population lower levels of sedentary behaviour have been associated with greater fitness, independent of peoples' physical activity level (Santos et al., 2014). Similar findings were also reported in a study with rheumatoid arthritis patients (Yu et al., 2015**.** In the current study, fitness level was associated with self-reported physical activity using the Godin Leisure Time Exercise

Questionnaire, but was not associated with either subjective or objective sedentary behaviour. This was in line with previous work in people with MS (Motl et al., 2017d). Their finding of a small variation in daily minutes of sedentary time (26%) across the sample, which reduces the chance of a correlation is also true in the current data, where sedentary time varies by only 10%. This low variation, with relatively high levels of sedentary behaviour among the sample suggests there was perhaps not enough variation to detect associations. In contrast to this self-reported physical activity in the current sample showed high variation (mean score 13.8, standard deviation 14.4). It would therefore be useful to include a larger sample with greater variation in both sedentary behaviour and fitness in order to explore the differences between these subjective and objective measures in more detail.

6.4.6 LIMITATIONS

The study is limited by the cross sectional nature of the data, from a single time point, which does not allow the investigation of cause and effect. Although including a broad range of ages and disease severity, the study has a relatively small sample size and is 80% female. The submaximal fitness test used was not appropriate for all participants meaning a full dataset was not obtained for this outcome, a potential source of bias. The mean PDDS of 3.5, equivalent to mild gait disability suggests that the results may not be generalizable to those with higher mobility disability. Despite a large number of analyses done on this data there were not many significant associations found, therefore it is possible that some of the findings occurred due to chance.

6.5 CONCLUSION

This study has shown that in line with previous work, this group of people with MS had low levels of physical activity, and high sedentary behaviour which are associated with lower subjective vitality and higher levels of depression. Higher MVPA and daily steps were associated with better balance, faster walking, and a better self-reported assessment of walking. The different associations of subjective and objective sedentary behaviour and physical activity with other measures highlight the importance of using both subjective and objective assessments to give a clearer picture of the activity and its impact on the person. Future work can aim to evaluate the effects of an exercise intervention on a range of subjective and objective measures related to physical and mental health in MS.

CHAPTER 7: A FEASIBILITY STUDY TO INVESTIGATE THE EFFECTS OF AN EXERCISE PROGRAMME ON PHYSICAL ACTIVITY, FUNCTION, WELLBEING AND BEHAVIOURAL REGULATION IN PEOPLE WITH MS

ABSTRACT

Background: Home exercise programmes similar to the Otago programme, incorporating a combination of strengthening, balance, and aerobic components have been proven to be beneficial to the physical and mental wellbeing symptoms of multiple sclerosis (MS). Other elements of successful exercise programmes include behaviour change support in the form of goal setting, exercise planning and monitoring. However engagement with home exercise is variable among people with MS and less is known about the engagement with these exercise programmes in people with more severe disability.

Objective: To conduct a feasibility study to assess engagement with and effectiveness of a home-based exercise programme designed for people with MS, which included strength training, balance and aerobic elements in people with MS with a range of disability.

Methods: Participants took part in a twelve-week home exercise programme consisting of strengthening sessions for five lower limb muscle groups, a range of balance exercises in sitting or standing, and sessions of walking. Each of the three types of exercise was performed at least twice weekly. The participants were randomly allocated to an internet group, with access to web-based resources to support their exercise programme and a control group, without access to these web resources. Outcome measures included device-measured physical activity and sedentary behaviour, walking ability measured by the Timed Up and Go, 25ft walking test and MS walking scale questionnaire. Functional balance was assessed by the Berg Balance scale. Wellbeing was measured using the Fatigue Severity Scale, Hospital Anxiety and Depression Scale, and scores for pain and Subjective Vitality. Behavioural measures related to exercise planning and goal setting were also taken.

Results: Fifteen participants (14 female and 1 male) provided data both at baseline and twelve weeks. Mean age was 52.9 (±9.5) years, and mean PDDS score was 3.4 (± 2.2). Self-reported engagement with the programme was good in both the internet and control group, and did not differ in those with lower and higher disability from their MS. Physical activity, functional ability, wellbeing and behavioural regulation did not change significantly although there were small non-significant improvements in gait speed, balance and fatigue as well as exercise goal setting and

planning. The internet group improved more in scores on the MS Impact scale than the control group.

Conclusions: The programme successfully encouraged regular self-reported exercise participation in both the internet and control groups, however no consistent improvements in physical activity, functional ability or wellbeing were reported. Enhancing the contact and behaviour change support offered by the researcher may have encouraged participants to exercise at a suitable intensity to achieve health benefits.

7.1 INTRODUCTION

Multiple sclerosis (MS) is a chronic inflammatory neurological disease with a broad range of symptoms impacting both physical and mental health. Common symptoms include fatigue, muscle weakness, spasms, and ataxia (Dobson and Giovannoni, 2019), all of which affect activities of daily living. Given that the onset of symptoms is typically between the ages of 20-40 years (Ford, 2020), MS can affect people across the lifespan. Psychological problems, including anxiety and depression, are experienced more frequently by people with MS compared to the general population (Marrie et al., 2015b). The general introduction to this thesis already identified benefits of structured exercise for people with MS. For example, exercise has been shown to improve lower limb strength, cardiorespiratory fitness (Platta et al., 2016b), fatigue (Pilutti et al., 2013b, Safari et al., 2017), and depression (Herring et al., 2017), as well as walking mobility (Pearson et al., 2015). As a result, research has argued for the inclusion of exercise as part of routine care for people with MS from early after diagnosis to assist in delaying disease activity and progression (Dalgas et al., 2019). Evidence-based guidelines for exercise in people with MS recommend two 30-minute sessions per week of moderate to vigorous physical exercise and twice weekly strength training (Latimer-Cheung et al., 2013a). These guidelines are based on evidence of the effects of exercise for people with MS with an EDSS score of up to 4.5 (Latimer-Cheung et al., 2013b). There is a relative lack of exercise studies, resulting in a poor evidence base for those with higher disability, therefore, these guidelines are for people with mild to moderate disease severity. In recognition of this, a recent consensus paper also endorsed including exercise throughout the disease course of MS including those who are non-ambulatory (EDSS of 7.0 and above) for whom guidelines do not exist (Kalb et al., 2020). More specifically, up to twenty minutes per day of assisted or independent exercise according to individual needs is suggested for those with EDSS of 7.0 and above. Activities can range from chair-based resistance exercises to functional movements such as manual wheelchair propulsion and transfers (Kalb et al., 2020).

7.1.1 BALANCE TRAINING IN MS

The exercise guidelines focus on aerobic and resistance exercise, as those are the most common types of exercise modalities used in the MS literature. However, balance training programmes have also received attention in MS. This is not surprising given that balance is a common problem for people with MS (Finlayson et al., 2006). Balance training has been shown to improve balance outcomes in MS, particularly when combined with gait and functional training (Gunn et al., 2015). Both standardised core exercises and Pilates programmes have been shown to improve walking speed and functional balance measures in people with MS (Fox et al., 2016, Freeman et al., 2010, Guclu-Gunduz et al., 2014, Forsberg et al., 2016, Küçük et al., 2016). A review also showed promising results of the effect of Pilates, which includes balance exercises, on fatigue (Sánchez-Lastra et al., 2019). These exercises can be easily adapted for people to do at home with two of the studies requiring 15 minutes of daily home exercises from participants (Fox et al., 2016, Freeman et al., 2010). Both studies reported over 80% adherence to the programmes. Importantly, these programmes were effective for people with more severe gait impairments (EDSS 4.0 – 6.5) (Fox et al., 2016, Freeman et al., 2010). Combining balance training with aerobic and strengthening exercises was shown to have beneficial effects on balance measures, gait speed, and endurance as well as improving fatigue (Sandroff et al., 2017, Sangelaji et al., 2014, Tarakci et al., 2013). Together, this suggests that combined balance, strength, and aerobic programmes may offer an opportunity for people with MS to improve balance outcomes, aerobic fitness, as well as benefits for symptoms such as fatigue.

7.1.2 THE OTAGO EXERCISE PROGRAMME

The Otago home exercise programme was developed for use with community-dwelling elderly people. It is a twelve-week programme which is shown to be effective in the prevention of falls through progressive exercises for lower limb strength, balance, and walking ability (Campbell and Robertson, 2003), problems which are also common in people with MS. The programme focuses on strengthening five lower limb muscle groups, along with targeted balance exercises and regular walking as an aerobic activity. A systematic review and meta-analysis showed that the Otago programme significantly reduced fall rates and risk of death in older adults, including many who were only mobile within their homes (Thomas et al., 2010). The weekly pattern of exercise in the Otago programme is very similar to that recommended in the MS exercise guidelines. For example, the Otago programme includes 30 minutes of walking twice per week, which, if conducted at a moderate intensity, is equivalent to the aerobic exercise element of the MS guidelines. The MS guidelines also recommend twice weekly strength training, which is similar to the strengthening of five key lower limb muscle groups in the Otago programme. The third aspect of the Otago programme is a series of standing balance exercises. This programme has been shown to be effective in improving timed up and go and Berg balance scale scores, as well as functional lower limb strength (Benavent-Caballer et al., 2016, Martins et al., 2018). Adherence to exercise sessions in the Otago programme was reported to be above 75% in some studies (Martins et al., 2018), showing that this programme is well tolerated by participants. Therefore, the Otago programme provides a good exercise plan for people with MS by combining the MS exercise guidelines with additional balance training.

7.1.3 HOME EXERCISE PROGRAMMES IN MS

The home-based aspect of the Otago programme makes it particularly suitable for people with MS-related mobility problems, or difficulties accessing exercise facilities. However, it is important to be aware that barriers to home exercise may need to be overcome. The qualitative data from people with MS in chapter 3 highlights problems staying motivated when exercising at home, suggesting the need for additional methods of support. From the perspective of health professionals, chapter 4 identified difficulties adapting an exercise programme given in hospital to the home setting as another potential barrier. Awareness of these barriers as viewed by both people with MS and health professionals is important to inform the delivery of the current programme. One example is visiting participants at home to advise on a suitable exercise environment and methods, as part of the exercise programme. Indeed, delivery of the Otago programme also incorporates visiting participants at home in order to review exercise technique and progress the programme as appropriate. The enhanced support of a home visit by the supervising therapist has been used before in rehabilitation for people with MS (Kersten et al., 2015b, Thomas et al., 2017), and viewed positively by both exercise participants and staff delivering the programme. The focus groups and interviews presented earlier in this thesis also identified the use of exercise diaries or exercise records as a facilitator for sticking to an exercise programme. Both people with MS and health professionals also spoke positively of other contact outside of exercise sessions, such as reminder text messages or progress calls. As well as the home visits, an exercise diary and schedule of regular telephone calls are also used as part of the support for adherence to the Otago programme. Engagement with the exercise programme based on number of recommended sessions done will be an outcome to be measured in the current study.

7.1.4 BEHAVIOUR CHANGE SUPPORT AND THE HEALTH ACTION PROCESS APPROACH

As well as exercise type and location of delivery, consideration should be given to the need for support for people with MS to take up and maintain their participation in an exercise programme. The Health Action Process Approach (HAPA) (Schwarzer et al., 2011) is a framework which describes behaviour change and the factors which underlie this, and has been applied in people with chronic health conditions. Briefly the model consists of a motivational phase where people form their intentions or goals, followed by a volitional phase where skills are developed to put the intentions into action. The HAPA also recognises the presence of barriers, which may hinder the new behaviour, as well as resources, which assist the adoption of the new behaviour. This framework has been advocated for use in MS (Schuler et al., 2019). The key behaviour change elements to be used in this study will be described below.

Based on previous exercise studies and the theoretical framework, the behavioural support in the intervention will include goal setting, and action and coping planning, as well as self-monitoring of exercise behaviour. In relation to goal setting, Motl et al. (2011) demonstrated that goal setting was associated with significant increases in physical activity in a twelve-week intervention. The motivational phase of the HAPA includes elements of goal setting. The formation of intentions are influenced by expectations of the outcome of the behaviour and risk perceptions, and self-efficacy for performing the task (Schwarzer et al., 2011). In MS, the importance of goals being SMART (specific, measurable, achievable, realistic and timed), and the educational process involving the patient and family to negotiate goals with the healthcare team have been highlighted (Khan et al., 2008). As well as supporting programmes of physical activity, goal setting as a part of exercise programmes is also increasingly used in MS. Results of exercise studies using goal setting, have shown increases in self-reported physical activity compared to control conditions (Thomas et al., 2017, Learmonth et al., 2017b, Carter et al., 2014).

Another element, also in line with the theoretical framework, is action planning, which is part of the volitional phase. The HAPA states that once goals or intentions have been formed, planning is an important method to ensure the intended behaviour is carried out (Schwarzer et al., 2011). In the current study this will involve the participants scheduling their exercise sessions throughout the week. In addition, and given the nature of the specific exercises of the Otago programme, participants will also be encouraged to set *if-then* plans. *If-then* plans are detailed action plans which use a specific situation as a trigger to perform the behaviour, bridging the gap between the goal or intention and associated action (Schwarzer et al 2008). These specify, for example *if* – I am in the kitchen washing dishes at 9.30 on Wednesday *then* - I will spend 15 minutes doing my leg exercises. They have been used successfully in MS. Participants reported they were helpful to support a mobility-focused home exercise programme (Kersten et al. 2015), suggesting that action planning in this particular way forms a valuable part of the support for exercise. In both healthy adults and participants with a range of clinical conditions including diabetes, heart disease, brain lesion and obesity, a systematic review investigated the use of if-then plans to increase physical activity (Silva et al., 2018). The review showed that this type of planning, particularly when studies included reinforcement of the plans part way through an intervention, successfully increased self-reported physical activity levels. Another meta-analysis in people with a range of mental health conditions also showed a large effect size of the use of implementation intentions on the attainment of health-related goals (Toli et al., 2016).

Another aspect which has been shown to enhance adherence to exercise programme are coping plans, which involve anticipating possible problems which may impede the achievement of goals and thinking of solutions for them. Participants will also be encouraged to formulate coping plans (Schwarzer et al., 2011). A facilitative plan is a type of coping plan. It is formed by the participant first thinking of occasions when they did, and when they did not, have control over their ability to exercise, with reasons. Participants then list three success factors, which would make it easier for them to stick to their exercise plan, and for each of these a way to bring this about. This method was effective in increasing daily walking in healthy participants (Darker et al., 2010). More recently this type of planning has been used in a physiotherapy-led intervention to increase physical activity in people with MS (Ryan et al., 2017). The twelve week intervention consisted of four one-to-one sessions each including focused discussion of personal barriers and facilitators to becoming more physically active. Participants were also supported to set weekly home physical activity goals using a behaviour change handbook. Compared to a usual care control group participants increased self-efficacy, as well as improving pain, fatigue and self-reported walking (Ryan et al., 2020). Facilitative plans may be especially relevant for people with MS, who may need to find ways of sustaining exercise programmes when fluctuating symptoms affect their motivation to exercise. Qualitative feedback from participants in the above study showed that they valued developing autonomy and competence in their ability to be more physically active (Fortune et al., 2019). The current study will utilise a facilitative plan as a way to encourage self-efficacy and problem solving in participants.

7.1.5 WEB-BASED DELIVERY OF EXERCISE IN MS

The use of web-based means to deliver exercise for people with MS is becoming increasingly popular. Research has found that people with MS value reputable internet sources of information about physical activity and its benefits due to its ease of access (Sweet et al., 2013, Casey et al., 2015). This suggests that study participants would be likely to consider engagement with a dedicated study website. Websites have been used for strengthening, balance, and aerobic exercise, as well as some combined programmes, enabling people to access a tailored exercise programme from home. Exercise websites designed for people with MS commonly include background information, specific information about exercise (including pictures or videos and exercise instructions), and an interactive area allowing the recording of exercise sessions in a diary. There is also usually an interface to contact the researchers in case of any questions or problems (Tallner et al., 2016, Donkers et al., 2020, Paul et al., 2014b, Conroy et al., 2018). Web-based home programmes may be particularly suitable for those with higher disability. This approach has been used in exercise programmes for people with MS with an EDSS of up to 6.0 resulting in improvements in mobility, leg strength, and physical activity (Donkers et al., 2020, Tallner et al., 2016). Compared to a control group without access to the website, more participants recorded twice weekly exercise (Donkers et al., 2020). Qualitative research also showed positive feedback from participants (Paul et al., 2014b). In chapter three of this thesis, people with MS were also positive about being able to quickly and easily record their exercises using an online diary, however there were concerns about exercise being done wrongly, going uncorrected without a face to face review from a health professional. In order to increase people’s confidence to exercise at home the internet site in the current study will offer detailed information, including photographs and written instructions for each exercise, as well as videos so that people also have the option of exercising in time with an instructor. Qualitative data from healthcare professionals in chapter four also identified positives regarding delivery and support of exercise online, particularly providing access to dedicated MS exercise websites and thus removing the need for people to search for suitable exercise programmes amongst the resources available on the internet. Movement quality when exercising was also identified as important by the health professionals. Videos could therefore enhance the quality of movement by showing an example of the exercise being done correctly. Both health professionals and people with MS suggested that not everyone with MS would be interested in using the internet to support exercise. Given the proven benefits of this method and the opportunity to make exercise accessible to larger numbers of people, reducing the resource implications for delivery, the current study will compare the outcomes of two groups; participants will be randomly allocated to an exercise group with access to an internet site to support participation or an exercise group without such access. The exercise component will be the same in both groups.

7.1.6 AIMS OF THE STUDY

Given the positive effects of exercise programmes which are similar to the Otago programme, incorporating strengthening, balance, and cardiovascular components on the symptoms of MS, this was a feasibility study of a new twelve-week home programme based on the same three components. The study also aimed to evaluate the effects of participating in this exercise programme on physical activity and sedentary behaviour. A further aim of the study was to assess levels of participation in each of the strength training, balance and aerobic elements of this exercise programme designed for people with MS. Finally, the study aimed to assess the effects of this exercise programme on functional ability, measures of wellbeing, and behavioural measures related to exercise planning and goal setting. Internet resources developed to support the exercise programme aimed to allow a comparison between an internet group who were given access to the resources and a control group who were not. The study aimed to recruit participants with a range of disability levels from their MS (up to EDSS 6.5). Another aim was to assess differences in outcomes between those with higher disability and those with lower disability levels.

7.2 METHODS

7.2.1 PARTICIPANTS

Participants were recruited from the outpatient MS clinics in the Dudley Group NHS Foundation Trust. Eligibility for the study was confirmed by the specialist nurse or consultant based on the following inclusion criteria: a consultant confirmed diagnosis of MS, being ambulatory, with an Expanded Disease Severity Scale score of up to 6.5 and having home internet access. Participants were excluded if they were pregnant, had any co-existing cardiovascular disease or other factors preventing safe participation in exercise or had experienced a relapse or any change to symptomatic or disease modifying medication within the last 30 days. Those who were currently participating in regular structured exercise programmes or having ongoing physiotherapy were also excluded. Ethical approval was provided by South Birmingham Ethics Committee. All participants gave written informed consent prior to participating in the study.

7.2.2 PROCEDURES

Participants attended two assessment visits before they started the exercise programme (time 1) and after they had completed the exercise programme (time 2). They were asked to avoid any strenuous activity for 24 hours prior to each visit and to refrain from a heavy meal, caffeine or smoking within two hours. During visit 1 (lasting approximately 90 minutes), the following assessments were taken: Timed 25ft walk, Berg Balance Scale, Timed Up and Go, Grip Strength. At the end of the visit participants were provided with an accelerometer to wear for the next 7 days. They were also given a questionnaire pack to complete at home, which included a demographic questionnaire as well as measures of wellbeing. Visit 2, which took place on average 12.0 (SD = 7.8) days following visit 1, lasted approximately one hour. During visit 2 participants returned the accelerometer and were asked to complete questionnaires relating to behavioural measures. The first session of the exercise programme also formed part of visit 2. Participants then completed the twelve-week exercise intervention, after which the assessments were repeated.

7.2.3 MEASURES

Outcome measures were the same as the outcome measures reported in Chapter 6. In addition, some assessments related to behavioural regulation were included. For an overview of all outcome measures, see Table 7.1. The outcome measures not mentioned in Chapter 6 in section 6.2 are described below.

Table 7.1: Baseline Assessments

Outcome	**Measurement**
Physical Activity	
Physical activity (objective) – including sedentary time, light intensity physical activity (LIPA), moderate/vigorous intensity physical activity (MVPA), and daily steps	Accelerometer (Actigraph GT3X)
Functional ability	
Gait speed and independence	Timed 25ft Walk (Motl et al., 2017a) Timed Up and Go (Podsiadlo and Richardson, 1991)
Balance	Berg Balance Scale (Berg et al., 1989)
Grip strength (dominant hand)	Dynamometer
Self-reported walking ability	MS Walking Scale (Hobart and Riazi, 2003)
Wellbeing	
Anxiety and depression	Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983)
Fatigue	Fatigue Severity Scale (Krupp et al., 1989)
Pain	Visual Analogue Pain Scale (Kersten et al., 2012)
Vitality	Subjective Vitality Scale (Ryan and Frederick, 1997)
Overall physical and psychological impact of MS	MS Impact Scale (physical and psychological subscales) (Hobart et al., 2001)
Behavioural measures	
Exercise goal setting and planning	Exercise Goal Setting Scale (goal setting and planning subscales) (Rovniak et al., 2002)
Outcome expectations for exercise	Multi-dimensional Outcome Expectations for Exercise Questionnaire (McAuley et al., 2010)
Determinants of planning and participating in regular exercise	Planned Behaviour Questionnaire (‘attitude’, ‘perceived behavioural control’, ‘subjective norm’ and ‘intention’ subscales) (Armitage, 2005)

QUESTIONNAIRES

Exercise Goal Setting Scale (Rovniak et al., 2002)

This questionnaire measures goal setting and planning in relation to exercise. It consists of two subscales, each containing ten items. The first subscale relates to exercise goals, e.g., “I usually achieve the exercise goals I set for myself”. The second subscale relates to exercise plans, e.g., “I plan my weekly exercise schedule”. The respondent is asked to indicate the extent to which each statement describes them from 1 ‘Does not describe’ to 5 ‘Describes completely’ allowing a total score to be calculated for exercise goal setting and a total for exercise planning. Higher scores indicate greater levels of goal setting and planning. In people with MS, overall scores for this questionnaire have shown a significant correlation with subjective physical activity ($p < .001$) (Ensari et al., 2017). The scale has been used in other studies targeting both increases in physical activity (Motl et al., 2011) and exercising at MS-specific guidelines (Coote et al., 2017).

Multidimensional Outcomes Expectations for Exercise Scale (McAuley et al., 2010)

This 15-item questionnaire measures a person’s expectations of the outcome of taking part in regular exercise using three subscales; physical subscale, social subscale, and self-evaluative subscale, each with five items. Example items of the subscales are: physical subscale “Exercise will aid in weight control”, social subscale “Exercise will provide companionship”, and self-evaluative subscale “Exercise will improve my mood”. Participants are asked to rate these items on a scale from 1 ‘Strongly disagree’ to 5 ‘Strongly agree’. A total score is calculated with higher scores showing more positive beliefs about exercise. This questionnaire has shown good internal consistency and all three subscales significantly correlated with self-reported physical activity and self-efficacy in people with MS (McAuley et al., 2010). The questionnaire has been used as an outcome measure for research into both exercise (Coote et al., 2017) and increasing physical activity in MS (Motl et al., 2011).

Planned Behaviour Questionnaire (Armitage, 2005)

This questionnaire measures feelings about planning and participating in regular exercise. Six questions relate to attitude and are scored on a seven point scale from –3 (e.g., dull, unpleasant, boring) to +3 (e.g., interesting, pleasant, stimulating). Three questions relate to subjective norm, exploring perceptions of the feelings of others, e.g., “People close to me think I should participate in regular exercise”. These are scored on a scale from 1 ‘Disagree’ to 7 ‘Agree’. Four questions relate to perceived behavioural control, e.g., “How confident are you that you will be able to participate in regular exercise?” These are scored on the same 1 to 7 scale, with higher scores showing greater perceived behavioural control. Two questions relate to behavioural intention asking about desire and frequency of intended exercise. These are also scored on the same 1 to 7 scale, with higher scores showing higher intention. Mean scores for each subscale are calculated. Internal reliability of all four subscales was good (Cronbach’s $\alpha = .72 – .90$) when measured at baseline and six-month follow up in a study into developing activity habits (Armitage, 2005).

Engagement with the exercise programme

Engagement with the exercise programme was calculated as the number of exercise sessions completed over the twelve weeks of the study. The target number of sessions was a minimum of two per week of “Strong” exercises, two per week of “Steady” exercises, and two per week of “Steps” exercises. Participants were provided with a paper exercise diary and were asked to record their weekly participation throughout the study. Those randomised to the internet group also had access to an online diary to record exercise sessions. Over the twelve weeks, a total of 72 sessions was recommended to each participant, comprising of 24 “Strong” exercise sessions, 24 “Steady” sessions, and 24 “Steps” sessions. Overall participation was therefore calculated as number of sessions of each type of exercise per week and expressed as a percentage of the total recommended sessions that were recorded by participants.

7.2.4 INTERVENTION

Participants were randomly allocated to either the internet or control group, stratified for sex, with the aim of recruiting similar numbers of male and female participants into each group. Randomisation was carried out by a computer programme. All participants, regardless of group allocation, took part in a twelve-week exercise programme. The exercise programme was the same in both groups, but the internet group had access to a dedicated website to support their participation which will be described below. The exercise programme used was based on the Otago exercise programme (Campbell and Robertson, 2003), designed as a strengthening, balance, and walking programme for elderly people to prevent falls and aid independent mobility at home. The programme was named “Strong Steady Steps”.

Strong Steady Steps Exercise Programme

Based on assessments of their strength, balance, and gait, participants were advised on a suitable level of exercise for each of the three parts of the programme. Different versions of each of the three types of exercise allowed the programme to be personalised to each participant’s ability. The target was two sessions of “Strong” exercises, two sessions of “Steady” exercise and two sessions of “Steps” exercises each week, which could progress to three times each week over the course of the programme on discussion with the researcher. Participants could choose the days of the week for each exercise dependent on personal commitments. They were advised to have at least a day’s rest between their two sessions of strengthening exercises. Exercise instructions and photographs of each exercise were detailed in an exercise booklet which was given to each participant for use at home. Each participant received two booklets: the exercise instruction booklet and the exercise diary mentioned above. The exercise diary also had space for participants to record a perceived difficulty level for each exercise on a particular day from 1 (very easy) to 10 (very difficult) and both daily and weekly reflective comments. An overview of the exercises included in the programme is given in Table 7.2.

Table 7.2: Strong Steady Steps Exercise Programme

EXERCISE TYPE	EXAMPLES	INTENSITY/FREQUENCY	PROGRESSION
STRONG – lower limb strengthening exercises	Knee extensions Knee flexions Hip abductions Plantarflexions Dorsiflexions	Five exercises For each, a single set of 10 repetitions with a rest if required increasing to two sets. Twice/thrice weekly	Addition/increase of weight Increase in repetitions or sets Change in speed
STEADY – balance and core stability/posture exercises – 3 or more of a possible 15 exercises	Sitting pelvic tilt Shoulder extensions Sit and reach up Sit to stand Standing knee bends Standing weight shift Tandem stand/walk Walking and turning Sideways/backwards walk Single leg stand Step and tap Tandem walk backwards Stair climbing	Minimum of three balance exercises chosen to create a challenge to balance. Twice/thrice weekly	Addition of weights. Increase in number or difficulty of balance exercises. Change in speed
STEPS – walking or other cardiovascular activity	Up to 30 minutes of walking at usual or brisk pace	Encouragement to walk briskly. Twice/thrice weekly	Increased speed of activity Longer walk with fewer breaks

Strong Exercises

Each participant was given an individualised version of each of the five “Strong” exercises based on brief assessments of their lower limb muscle strength. If appropriate 0.5 or 1 kg ankle weights were provided to some participants. During assessment visit 2, the researcher guided each participant through a complete session of all five “Strong” exercises to ensure appropriate pacing and rests. The exercises were demonstrated by the researcher with emphasis on isolating the movement to the correct muscle group and ensuring movement quality. Starting intensity of the exercises was determined by how much participants could comfortably do at the initial assessment. The intensity of exercise was then set at a level to be challenging but not impossible to complete. Participants were taught to use the perceived difficulty level of 1-10 as described earlier to assess this, with the starting intensity corresponding to approximately 6/10 on the scale. The aim was to build up to two sets of ten repetitions of each exercise twice or thrice weekly. Duration of “Strong” sessions was approximately 10 minutes at the start of the twelve weeks, with increases in sets or repetitions over the course of the programme. By the end of the programme, it was expected that “Strong” sessions would last 20-30 minutes. In order to maintain the intensity, progression to a more challenging version of each exercise (for example the addition of a weight or an increase in the weight) could be done in discussion with the researcher based on feedback and reflections of perceived difficulty level.

Steady Exercises

Participants were given a minimum of three of a possible fifteen “Steady” exercises based on their assessments of walking and balance. Exercises could be done in sitting, standing or walking, with the aim being a starting approximate difficulty level of 6/10. 0.5 or 1 kg hand weights were necessary for some exercises and provided to participants as appropriate. A full “Steady” exercise session was carried out by the participant guided by the researcher during assessment visit 2. All exercises were demonstrated by the researcher, ensuring participant safety with recommendations for suitable physical support when needed. The aim was to exercise twice weekly progressing to thrice weekly. At the start of the programme “Steady” exercise sessions were expected to last 10-15 minutes. During the twelve-week programme, progression could include adding more “Steady” exercises or increasing the length of time for each exercise to create a longer exercise session. The “Steady” exercise session could also be made more intense with standing or walking exercises instead of exercises in sitting, and by removing the physical support used by the participant. Duration of “Steady” sessions could therefore increase to 30-40 minutes by the end of the twelve weeks. Progression could be planned in discussion with the researcher based on feedback and reflections of perceived difficulty level.

Steps Exercises

During assessment visit 2, the “Steps” component of each participant’s exercise programme was discussed. The aim was to walk briskly for up to 30 minutes twice per week, which like the other types of exercises could increase to three times per week. Most participants carried out “Steps” sessions of 10-15 minutes at a time when they started the exercise programme. Participants were encouraged to consider how this could be incorporated into their regular everyday activities. They were advised to begin walking at their usual pace. Discussion and information in the exercise booklet included definitions of light moderate and vigorous intensity walking, with advice on how to build up time spent walking and how to make the walking more intense by increasing speed. Several participants had home exercise equipment (treadmill, exercise bike or cross trainer) which they preferred to use for the “Steps” exercises as a safer or more convenient alternative to walking outside. For those participants the researcher discussed progression of the exercise in a similar way.

Behaviour Change Support

All participants were given an exercise booklet and an exercise diary. The exercise booklet had pictures and text detailing all exercises as well as their purpose. The diary comprised space to record daily exercises over the twelve weeks and perceived difficulty level for each as well as space for weekly goal setting and reflections on each type of exercise. During assessment visit 2, the researcher used the exercise diary to give guidance on how to plan their exercises at the start of a week according to their other commitments and to allow at least one rest day between strengthening sessions. Table 7.3 shows an example which was included in the exercise diary as a guide.

Table 7.3: Example of a week doing the Strong Steady Steps Exercise Programme

Day	STRONG exercises	STEADY exercises	STEPS exercises
Monday	10 repetitions of: 1. Heel raises 2. Toe raises 3. Knee flexions 4. Knee extensions 5. Hip abductions without weights	*REST*	*REST*
Tuesday	*REST*	Seated balance exercises Two minutes of: 1. Pelvic tilts 2. Reaching with alternate arms 3. Shoulder extensions 4. Sit to stand x 5	*REST*
Wednesday	*REST*	*REST*	30 minutes of walking in three 10-minute bouts
Thursday	*REST*	*REST*	*REST*
Friday	10 repetitions of: 1. Heel raises 2. Toe raises 3. Knee flexions 4. Knee extensions 5. Hip abductions without weights	*REST*	*REST*
Saturday	*REST*	Seated balance exercises Two minutes of: 1. Pelvic tilts 2. Reaching with alternate arms 3. Shoulder extensions Sit to stand x 5	*REST*
Sunday	*REST*	*REST*	30 minutes of walking in three 10-minute bouts

At this second assessment visit, individual goals for the first week of the intervention were discussed with the researcher and noted in the diary. The exercise diary also had space for the recording of *if-then* implementation intentions to specify clearly where when and how each exercise would be done. A third visit was conducted in the participant's home one week after they had started their exercise programme. At this visit, the researcher supported participants to set goals for the next week of their exercise programme. These goals were supported by *if-then* implementation intentions specifying where when and how each exercise would be done. To support them in overcoming barriers to exercise, participants were also assisted in creating a facilitative plan. The behaviour change aspects of the exercise programme were based on the Health Action Process Approach (HAPA) (Schwarzer et al., 2011). Support for behaviour change was offered throughout participation in the programme and is detailed in Table 7.4.

Table 7.4: Timing and Support for Behaviour Change in the Strong Steady Steps Programme

TIME	CONSULTATION	CONTACT	LOCATION	SUPPORT
One week prior to start of exercise programme	Visit 1	Face to face	Outpatient clinic	Discuss benefits of exercise in MS. Answer participant questions regarding exercise programme and study
Start of exercise programme	Visit 2	Face to face	Outpatient clinic	Teach specific exercises and give exercise booklet for home use Discuss detail of where, when and how exercises will be done Set goals for first week of exercise programme. Give exercise diary and demonstrate its use 1) to record daily exercise participation and difficulty 2) to record weekly goals and reflection on progress for self-monitoring
One week	Visit 3	Face to face	Participant's home	Review and modify exercises if needed Discuss personal reflection on first week of exercise Using exercise diary set goals for next week of exercise programme supported by *if-then* implementation intentions specifying where when and how exercise will be done Formulate facilitative plan to support overcoming barriers to exercise
Four weeks	Review call	Telephone	NA	Discuss personal reflection on current progress with exercise Verbal review and discuss modifications to exercises if needed Set ongoing goals
Twelve weeks		Face to face	Outpatient clinic	Discuss progress over the course of the programme and ongoing commitment to exercise Create follow-up goals and discuss how these will be achieved

Ongoing support

All participants carried out their exercises at home using the appropriate resources for support. They were able to contact a member of the research team by telephone or email for advice at any point. Four weeks after they had started their exercises all participants were contacted by telephone. The purpose of this call was to discuss their reflections on exercise progress and set ongoing goals. Modifications to their exercises were also recommended if needed. At the end of their twelve week programme a follow-up visit provided the opportunity to discuss their progress over the course of the programme. Participants' ongoing commitment to exercise was also discussed. They were supported to create follow-up goals and discuss their plans of how goals could be achieved.

INTERNET GROUP

At visit 2, participants allocated to the internet group, received an additional information sheet related to the web-based resources. They were given the opportunity to ask questions about this element, and then provided signed informed consent to use the resources. Following this the website was demonstrated to them in order that they could access the information and record their exercise sessions online. Those in the control group were not made aware of the web-based resources.

Website content

Participants allocated to the internet group had access to a dedicated study website at https://strong-steady-steps.bham.ac.uk/ Each participant chose a password to access their personalised area of the site. The main areas of the site were as follows:

a) ***Exercise in MS*** – general information about the benefits of exercise for people with MS including published exercise guidelines and the effects on symptoms. The concepts of lifestyle physical activity and sedentary behaviour are also introduced with information about the benefits of increasing physical activity and reducing sedentary behaviour.

b) ***About the programme*** – information about each of the three specific types of exercise included in the programme and the purpose of each exercise. Photographs and video clips of people performing each exercise and detailing safety precautions were also available here.

c) ***My Exercise programme*** – a calendar to plan exercise sessions. Participants could record repetitions and duration of exercises done on each day, together with a rated difficulty level from 1 (very easy) to 10 (very difficult) and reflective comments. The site generated graphs displaying this information, allowing participants to look back over the course of their exercise programme for self-monitoring of their exercise behaviour. This information was also available to the research team who could review both frequency of engagement with the website and their exercises.

d) ***Prepare and plan*** – information about safety during exercise, and progression of exercise. Guidance about the use of an exercise diary and about the setting of exercise goals with examples.

e) ***Staying motivated*** – information about sticking to the exercise programme such as advice on overcoming challenges e.g. pain or fatigue. This area also included Information on continuing to exercise after the twelve week programme finished.

7.2.5 DATA REDUCTION AND ANALYSIS

Data from questionnaires and baseline assessments were entered into a database and examined for normality, missing data and outliers. In fewer than 25% of cases the answer to a single question on a questionnaire was missing. Substitute values were calculated using a 'personal mean score', a mean of the individual participant's scores for other items of the subscale (Peyre et al., 2011). As reported in the previous chapter, for the accelerometer data a daily average was calculated and used in the analysis. Two participants failed to return questionnaire packs at time 2. Three participants did not provide four or more valid days of accelerometer data including a weekend day at time 2, and therefore their data could not be included in the analysis. All analyses were conducted using SPSS Statistics version 26 (SPSS Inc., Chicago, IL) and as data was not normally distributed, non-parametric tests were conducted.

Wilcoxon signed rank tests were used to assess within group differences at time 1 (baseline assessment) and time 2 (post-intervention) for the internet and control group separately. Subsequently, a change score was calculated as the difference between time 2 and time 1. Wilcoxon signed ranked tests were used to explore any differences between groups in these changes.

Given the interest in assessing the effects of this intervention on people with a range of disability, the data is presented separately for those with low disability level (PDDS ≤ 3) and higher disability level (PDDS ≥ 4). This was done for descriptive purposes only, no formal statistical analyses were conducted on this.

7.3 RESULTS

7.3.1 PARTICIPANTS

Thirty participants attended baseline assessments (see Chapter 6), and for fifteen participants data was available at both baseline and 12 weeks. Reasons given for not continuing with the programme were: MS relapse (n=2), ongoing mental health problems (n=2), other unrelated health problems (n=5), family reasons (n=2), and no reason given (n=4). Dropout rates were similar for the internet group (n=7) and the control group (n=8). Independent samples Mann-Whitney U tests showed that there were no differences between completers and dropouts for the majority of baseline measures. The only difference between the two groups was for the Exercise Goal Setting Questionnaire, with completers scoring higher than dropouts on the Exercise Goal Setting subscale (p= .009) and the Exercise Planning subscale (p= .022). Table 7.5 shows the demographic information for the 15 participants with data at both time points; one male and 14 females. Fourteen identified as white British and one as Indian. Seven were randomised to the internet exercise group and eight to the control group. Mann-Whitney U tests showed that there were no baseline differences between the internet and control groups.

Table 7.5: Participant demographic information

	All participants (n=15)		**Internet Group (n=7)**		**Control Group (n=8)**	
	Mean (SD)	Median (range)	Mean (SD)	Median (range)	Mean (SD)	Median (range)
Age (years)	52.9 (± 9.5)	50 (35 – 67)	54.4 (± 10.7)	56 (35 – 65)	51.6 (± 8.8)	46.5 (45 – 67)
Gender	F = 14	M = 1	F = 6	M = 1	F = 8	M = 0
PDDS	3.4 (± 2.2)	3 (0 – 7)	3.9 (± 2.4)	4 (0 – 7)	3.0 (± 2.1)	3 (0 – 6)
Disease duration (years)	10.5 (± 6.7)	10 (2 – 27)	12.3 (± 9.2)	13 (2-27)	8.9 (±3.5)	9 (3 – 13)

Note: F: female, M: male, PDDS: Patient Determined Disease Steps

7.3.2 ENGAGEMENT WITH THE EXERCISE PROGRAMME

Two participants in the internet group did not use the online diary, but recorded all their exercise sessions in the paper diary booklet. Two other participants in the internet group, and one participant in the control group also reported having used the paper diary booklet, but their diaries were not returned. Table 7.6 reports the self-recorded exercise data for each participant of the internet group and Table 7.7 reports this for each participant in the control group over the twelve weeks of the study, with participants grouped according to lower and higher PDDS for descriptive purposes only. The internet group recorded 1.4 (± 0.9) or 72% of recommended ‘Strong’ exercise sessions, 1.4 (± 0.9) or 69% ‘Steady’ sessions and 1.2 (± 1.2) or 60% ‘Steps’ sessions per week. The control group recorded 1.6 (± 1.2) or 80% of recommended ‘Strong’ exercise sessions, 2.0 (± 1.9) or 102% ‘Steady’ sessions, and 1.8 (± 1.9) or 92% ‘Steps’ sessions per week. Adherence appeared to be similar in those with both higher and lower disease severity. Information about goal setting was not captured on the website. However, all of those who used paper diaries used the weekly goal setting section for a mean of 9.2 (± 3.2) weeks.

Table 7.6: Reported Strong Steady Steps exercise sessions for the internet group

PDDS	WEEK											
	1	2	3	4	5	6	7	8	9	10	11	12
≤ 3	🟦🟦🟦🟦 🟧🟧🟧🟧 🟧🟧	🟦🟦 🟧🟧	🟦🟦 🟧🟧🟧 🟩	🟦🟦🟦 🟧🟧🟧 🟩	🟦🟦🟦 🟧🟧🟧 🟩🟩	🟦🟦🟦 🟧🟧🟧	🟦🟦 🟧🟧	🟦	🟦 🟧	🟦🟦 🟧🟧 🟩	🟦🟦 🟧🟧 🟩	🟦🟦 🟧🟧🟧
≤ 3	🟦🟦 🟧🟧 🟩	🟦🟦🟦 🟧🟧 🟩	🟧 🟩🟩	🟦 🟩🟩🟩	🟦🟦🟦 🟧	🟦🟦 🟧🟧	🟦🟦 🟧 🟩🟩	🟦🟦 🟧 🟩🟩🟩	🟦🟦 🟧 🟩🟩🟩	🟦🟦 🟧🟧 🟩	🟦🟦 🟧🟧 🟩	🟦🟦 🟧🟧 🟩🟩
≤ 3	🟦 🟧	🟦 🟧										
≥ 4 ^	🟦🟦 🟧🟧 🟩🟩🟩	🟦🟦 🟧🟧 🟩🟩🟩	🟦🟦 🟧🟧 🟩🟩🟩	🟦🟦 🟧🟧 🟩🟩	🟦 🟧🟧 🟩🟩🟩	🟦🟦 🟧🟧 🟩🟩🟩	🟦 🟧🟧 🟩🟩🟩	🟦🟦 🟧🟧 🟩🟩🟩	🟦 🟧 🟩	🟦🟦 🟧🟧 🟩🟩	🟦🟦 🟧🟧 🟩🟩🟩	🟦🟦 🟧🟧 🟩🟩🟩
≥ 4	🟦🟦 🟧🟧 🟩🟩	🟦🟦🟦🟦 🟧 🟩🟩🟩	🟦🟦 🟧🟧 🟩🟩🟩	🟦🟦 🟧 🟩	🟦🟦 🟧 🟩	🟦🟦🟦 🟧🟧	🟦🟦 🟧	🟦🟦 🟧🟧	🟦🟦🟦 🟧🟧	🟦🟦🟦 🟧🟧	🟦🟦 🟧🟧	🟧🟧
≥ 4	🟦🟦	🟧										
≥ 4 ^	🟦🟦 🟧🟧 🟩🟩	🟦🟦 🟧🟧 🟩🟩🟩	🟦 🟧🟧 🟩🟩🟩🟩	🟦🟦 🟧🟧 🟩🟩🟩	🟦🟦 🟧🟧 🟩🟩🟩	🟦🟦 🟧🟧 🟩🟩🟩	🟦🟦 🟧🟧 🟩🟩🟩	🟦 🟧🟧 🟩🟩🟩	🟦 🟧🟧 🟩🟩🟩	🟦🟦 🟧🟧 🟩🟩🟩	🟦🟦 🟧🟧 🟩🟩🟩	🟧

Note: Each line of the table shows data for one participant, ^ denotes recorded in paper rather than online diary

🟦= STRONG EXERCISE SESSION

🟧= STEADY EXERCISE SESSION

🟩= STEPS EXERCISE SESSION

Table 7.7: Reported Strong Steady Steps exercise sessions for the control group

PDDS	WEEK											
	1	2	3	4	5	6	7	8	9	10	11	12
≤3	🟦🟦🟦 🟧🟧 🟩🟩	🟦 🟧🟧 🟩🟩	🟦 🟧🟧 🟩🟩	🟦🟦 🟧🟧 🟩🟩	🟦🟦 🟧 🟩🟩		🟩🟩🟩🟩	🟩				
≤3	🟦🟦🟦🟦 🟧🟧🟧 🟩🟩🟩🟩 🟩🟩🟩	🟦🟦🟦🟦 🟧🟧🟧🟧 🟧🟧🟧 🟩🟩🟩🟩 🟩🟩🟩	🟦🟦 🟧🟧🟧🟧 🟧🟧	🟦🟦🟦 🟧🟧🟧🟧 🟧🟧🟧 🟩🟩🟩🟩 🟩🟩🟩	🟦🟦🟦 🟧🟧🟧🟧 🟧🟧🟧 🟩🟩🟩🟩 🟩🟩🟩	🟦🟦🟦 🟧🟧🟧🟧 🟧🟧🟧 🟩🟩🟩🟩 🟩🟩	🟦🟦🟦 🟧🟧🟧🟧 🟧🟧🟧 🟩🟩🟩🟩	🟦🟦🟦 🟧🟧🟧🟧 🟧🟧🟧 🟩🟩🟩🟩 🟩🟩	🟦🟦🟦 🟧🟧🟧🟧 🟧🟧🟧 🟩🟩🟩🟩 🟩🟩	🟦🟦🟦 🟧🟧🟧🟧 🟧🟧🟧	🟩🟩	🟦🟦🟦 🟧🟧🟧🟧 🟧🟧🟧 🟩🟩🟩🟩 🟩🟩
≤3	🟦🟦 🟧 🟩	🟦🟦 🟧🟧 🟩🟩	🟦🟦 🟧🟧 🟩	🟦🟦 🟧🟧 🟩	🟦 🟧🟧 🟩	🟦🟦 🟧🟧 🟩	🟦🟦 🟧🟧 🟩	🟦🟦 🟧🟧 🟩	🟦🟦 🟧🟧 🟩	🟦🟦 🟧🟧 🟩	🟦🟦 🟧🟧 🟩	
≤3	🟦🟦 🟧🟧 🟩🟩	🟦 🟧🟧		🟦🟦 🟧🟧 🟩🟩	🟦🟦 🟧🟧 🟩🟩		🟦🟦 🟧🟧🟧 🟩	🟧	🟦 🟧 🟩			
≤3												
≥4	🟦🟦 🟧🟧 🟩	🟦🟦 🟧🟧🟧 🟩	🟦🟦 🟧🟧 🟩	🟦🟦 🟩🟩	🟦 🟧🟧🟧 🟩🟩🟩	🟦🟦 🟧🟧	🟦🟦 🟧🟧 🟩🟩🟩	🟦🟦 🟧🟧	🟦 🟧🟧🟧 🟩	🟦 🟧 🟩	🟦🟦 🟧🟧	🟦🟦 🟧🟧 🟩
≥4	🟦🟦 🟧🟧 🟩🟩	🟦🟦 🟧🟧 🟩🟩	🟦 🟧 🟩			🟦 🟩 🟩	🟦🟦 🟧🟧 🟩🟩	🟦🟦 🟧🟧 🟩🟩	🟦 🟧🟧 🟩	🟦 🟧 🟩	🟧🟧	🟦🟦 🟧🟧 🟩
≥4	🟦 🟧 🟩🟩	🟦🟦🟦 🟧🟧🟧 🟩🟩🟩🟩 🟩	🟦🟦🟦🟦 🟧🟧🟧🟧 🟩🟩🟩🟩 🟩🟩	🟦🟦 🟧🟧 🟩🟩🟩🟩 🟩	🟦🟦🟦 🟧🟧🟧 🟩🟩🟩	🟦🟦 🟧🟧 🟩🟩🟩🟩	🟦🟦🟦🟦 🟦🟦 🟧🟧🟧🟧 🟧 🟩🟩🟩🟩	🟦🟦🟦🟦 🟦🟦 🟧🟧🟧🟧 🟩🟩🟩🟩 🟩🟩	🟦🟦🟦🟦 🟦 🟧🟧🟧 🟩🟩🟩🟩 🟩	🟦🟦🟦🟦 🟦 🟧🟧🟧🟧 🟩🟩🟩🟩 🟩	🟦🟦🟦🟦 🟦 🟧🟧🟧 🟩🟩🟩🟩 🟩🟩	🟦🟦🟦 🟧🟧 🟩🟩🟩🟩 🟩🟩🟩

Note: Each line of the table shows data for one participant

🟦= STRONG EXERCISE SESSION

🟧= STEADY EXERCISE SESSION

🟩= STEPS EXERCISE SESSION

7.3.3 EFFECTS OF THE INTERVENTION – PHYSICAL ACTIVITY

Figure 7.1 shows individual participant data for the internet and control groups at baseline and at 12 weeks. Within group analyses using Wilcoxon signed rank tests showed no changes from baseline to 12 weeks in LIPA, MVPA, daily steps or sedentary behaviour in either group (p’s> .34). Wilcoxon signed rank tests also revealed no differences in the changes from baseline to 12 weeks between the internet and control group (p’s> .31). As is clear from the individual data presented in the graphs, there were substantial individual differences in the responses (Figure 7.1), with little impact of intervention group or PDDS on these individual differences. For both MVPA and steps, the variability between participants was small for the internet group. More variability was seen in the control group, both with regards to MVPA and steps at baseline as well as changes in MVPA following the intervention, with apparently little impact of PDDS.

7.3.4 EFFECTS OF THE INTERVENTION – FUNCTIONAL ABILITY

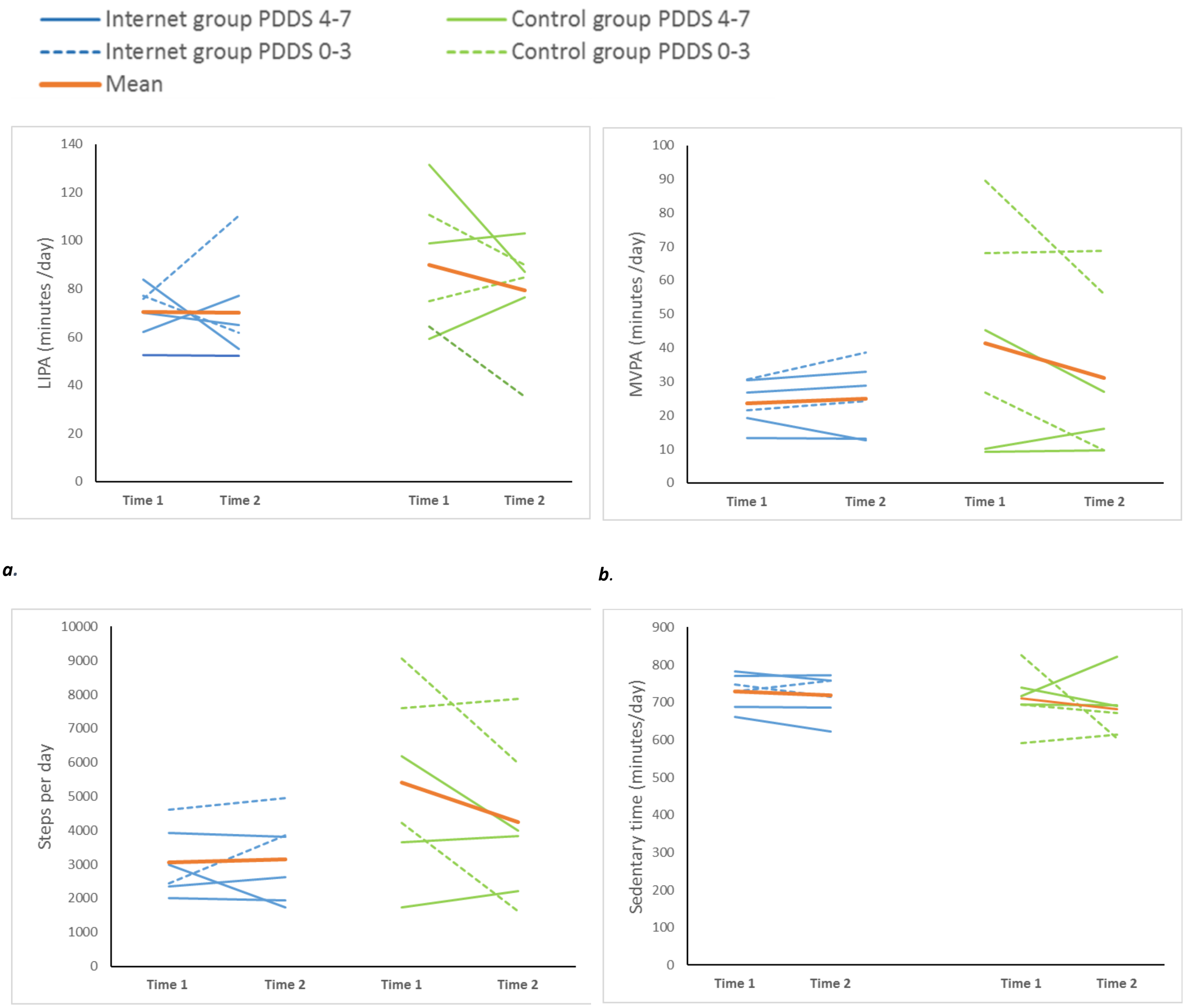
Figure 7.2 shows individual participant data for Berg Balance scale, Timed Up and Go, 25ft Timed Walk, MS Walking Scale, and Grip at baseline and at 12 weeks. Statistical analysis using Wilcoxon signed rank tests showed no changes from baseline to twelve weeks in either the internet or the control group for any of the functional ability measures (p’s> .07). Wilcoxon signed rank tests also showed no significant changes for any of these outcomes from time 1 to time 2 between the internet and control groups (p’s> .54). As expected, the scores for function, both subjectively and objectively measured, were generally higher in those with lower PDDS. Changes in scores were variable, and the variation was not consistent within the lower and higher disability groups.

7.3.5 EFFECTS OF THE INTERVENTION – WELLBEING MEASURES

Figure 7.3 shows individual participant data plots for anxiety, depression, fatigue, vitality, pain, and MS Impact. Wilcoxon signed rank tests showed no changes from baseline to twelve weeks in either the internet or the control group for the five wellbeing measures (p’s> .11). Wilcoxon signed rank tests also showed no significant changes in most of these outcomes from time 1 to time 2 between the internet and control groups (p’s>.05). The MSIS Psychological scores decreased in the internet group and increased slightly in the control group, but these within group changes were not significant. This was the only outcome where the change in score from time 1 to time 2 was significantly different between the internet and control groups (p= .005). The wellbeing measures were also generally better for those with lower disability, but there was variability in both overall scores and changes in scores.

7.3.6 EFFECTS OF THE INTERVENTION – BEHAVIOURAL REGULATION

Figure 7.4 shows individual participant data plots for the Exercise Goal Setting Scale, Planned Behaviour Questionnaire and Multidimensional Outcomes Expectation for Exercise Scale. Statistical analysis using Wilcoxon signed rank tests showed no changes from baseline to twelve weeks in either the internet or the control group for the behavioural measures (p's> .12). Wilcoxon signed rank tests also showed no significant changes for any of these outcomes from time 1 to time 2 between the internet and control groups (p's> .18). The Exercise Goal Setting Scale showed an increase in both exercise goal setting and exercise planning for both groups, with the biggest individual increases in low PDDS participants (Figures 7.4a and b). For the Planned Behaviour Questionnaire, all four subscales showed a slight and non-significant increase in the internet group (Figures 7.4c – f). The Subjective Norm subscale was the only one which increased in both groups (Figure 7.4e). The Multidimensional Outcomes Expectation for Exercise Scale showed little variation and very little change from time 1 to time 2 (Figure 7.4g).



a.

b.

c.

d.

Figure 7.1 Individual Participant Physical Activity Data at Time 1 and Time 2: a. Light Intensity Physical Activity (minutes/day), b. Moderate/Vigorous Intensity Physical Activity (minutes/day), c. Steps per day, d. Sedentary Time (minutes/day)

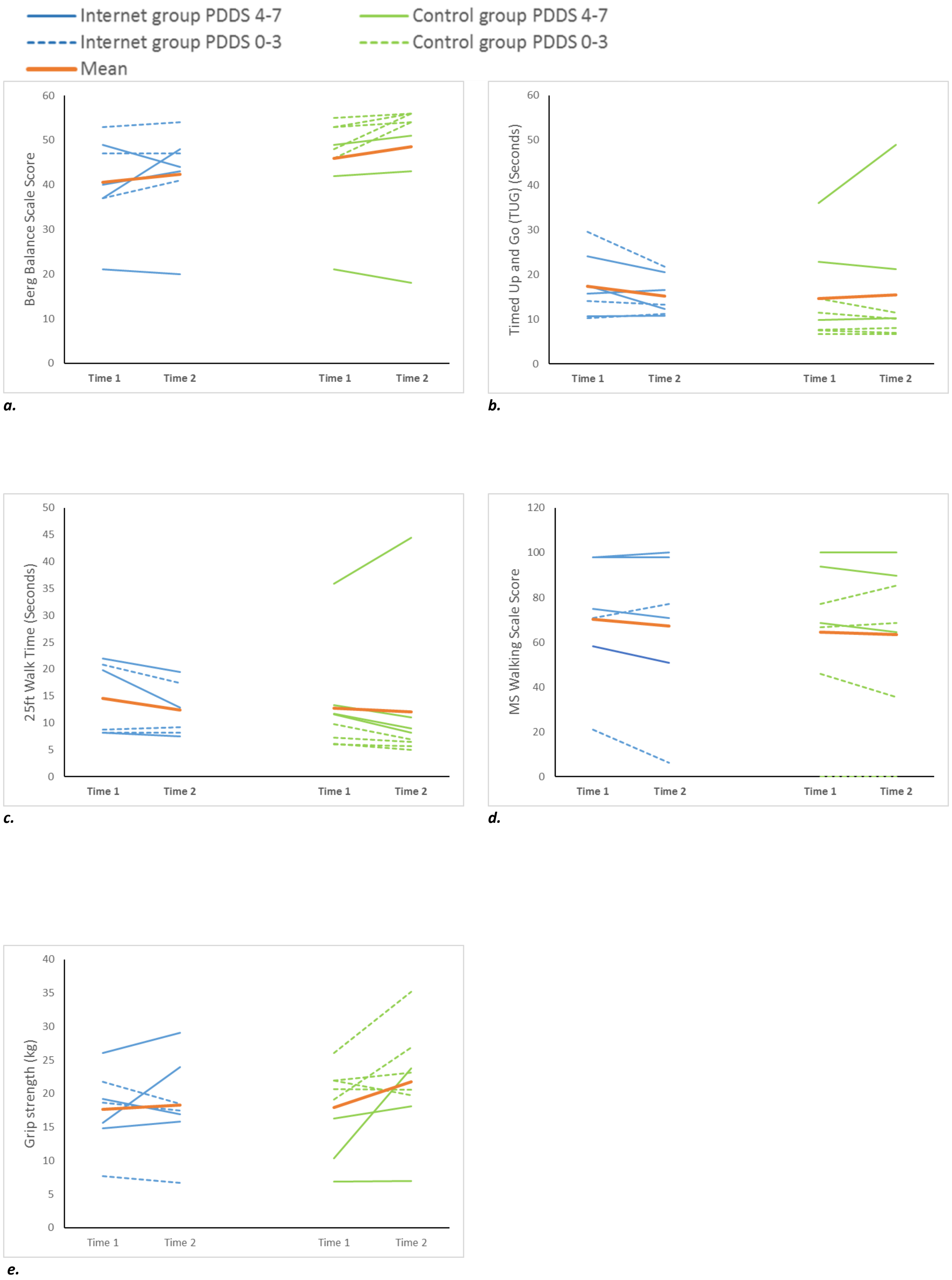
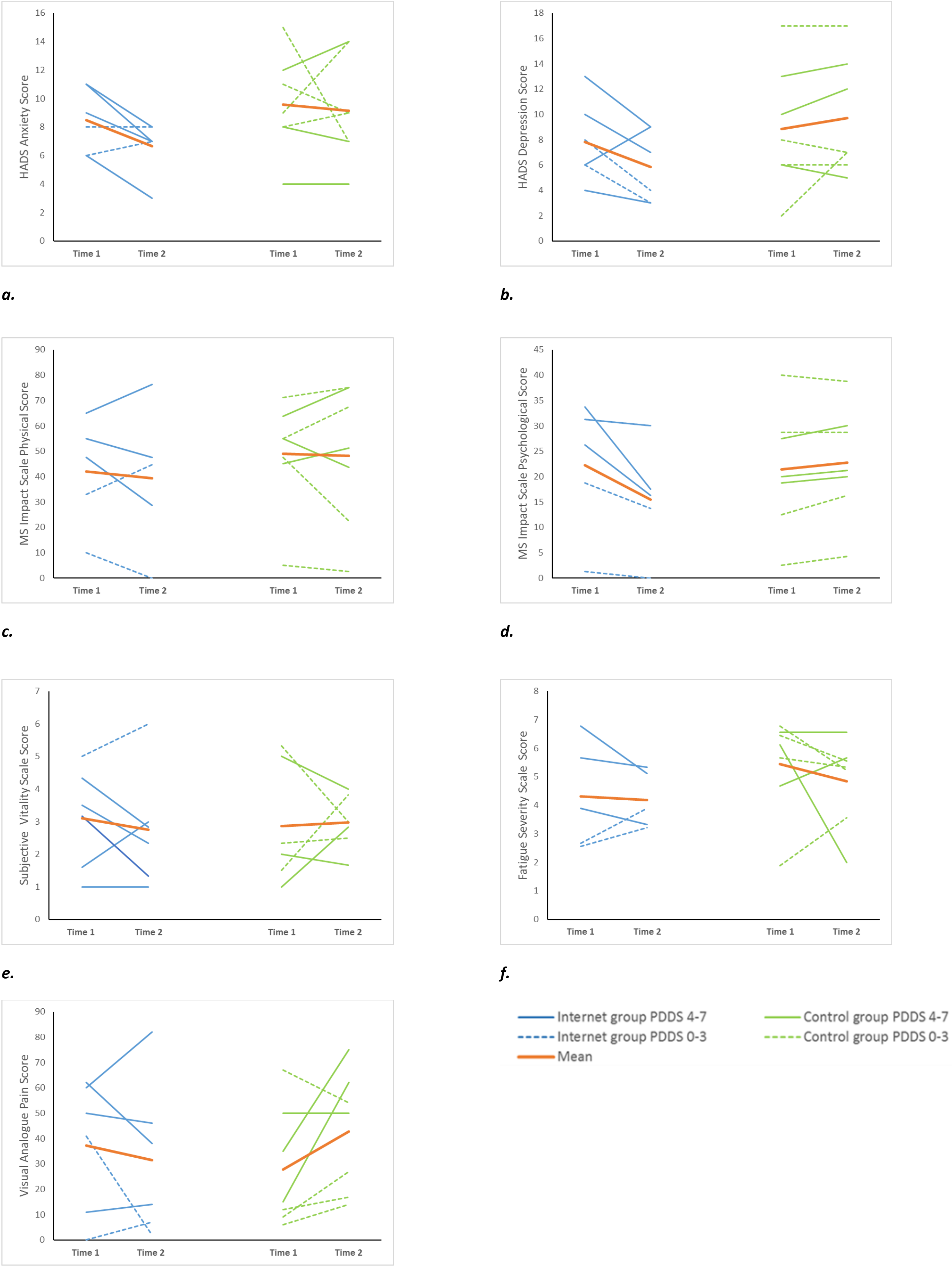


Figure 7.2 Individual Participant Functional Ability Data at Time 1 and Time 2: a. Berg Balance Scale Score, b. Timed Up and Go (seconds), c. 25ft Timed Walk (seconds), d. MS Walking Scale Score, e. Grip Strength (kg)



a.

b.

c.

d.

e.

f.

g.

Figure 7.3 Individual Participant Wellbeing Data at Time 1 and Time 2: a. HADS Anxiety, b. HADS Depression, c. MS Impact Scale (Physical) d.MS Impact Scale (Psychological) e. Subjective Vitality Scale, f. Fatigue Severity Scale, g. Visual Analogue Pain Scale

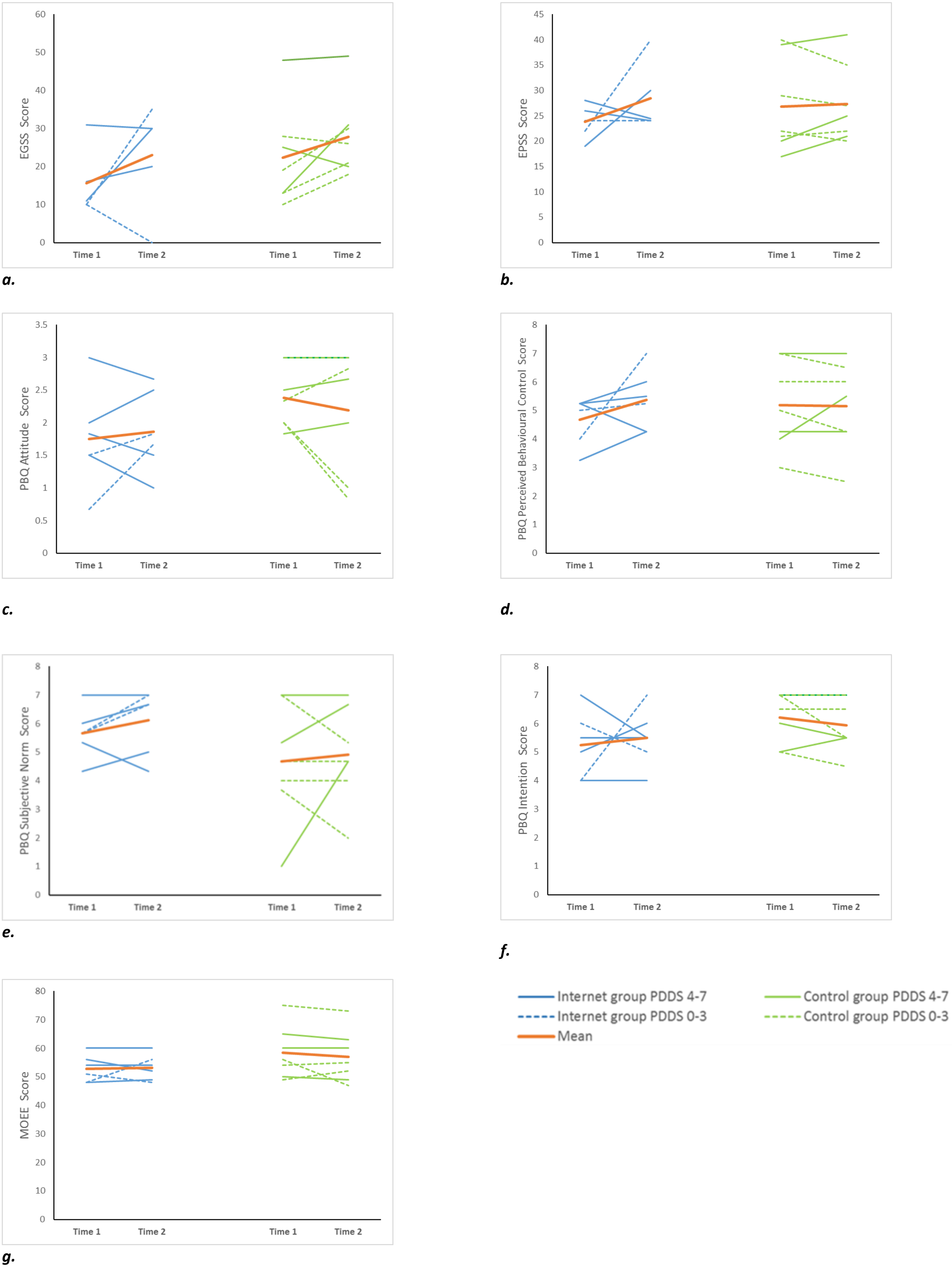


Figure 7.4 Individual Participant Data for Behavioural Measures at Time 1 and Time 2: a. Exercise Goal Setting Scale, b. Exercise Planning Scale, c. Planned Behaviour Questionnaire (PBQ) Attitude d. PBQ Perceived Behaviour Control e. PBQ Subjective Norm, f. PBQ Intention, g. Multidimensional Outcomes Expectation for Exercise Scale (MOEE)

7.4 DISCUSSION

The study aimed to explore the engagement with and the effects of a home exercise programme for people with MS across a range of disability levels. In addition, engagement with and effectiveness of two different ways of delivering the programme was compared. One group of participants (the internet group) was given access to internet resources to support their programme, while the control group did not have the use of these resources.

7.4.1 ENGAGEMENT WITH THE EXERCISE PROGRAMME

Overall reported adherence to the programme was good: 67% for the internet group and 91% for the control group. This was similar for each of the three types of exercises, with no differences between low and high PDDS. This is higher than other home-based exercise studies, which have reported adherence of 45% or below (Conroy et al., 2018, Williams et al., 2021). Regarding engagement with the website itself, only three out of seven participants in the online group used the website to record exercises on at least a weekly basis across the twelve weeks. Others either preferred to use a paper diary to record exercise sessions throughout, or used the website only in the initial weeks. Information regarding website use other than to record exercise was not captured, so it is not known whether members of the online group used other areas of the site, e.g., videos of exercises being performed, the goal setting and exercise planning function, or tips for overcoming challenges. Qualitative work has shown that people with MS value the use of the internet as a source of information about exercise for its' accessibility and potential for interaction (Sweet et al., 2013, Learmonth et al., 2019). However, there is also evidence that elements not included in the Strong Steady Steps website, such as exercise success stories from others with MS are viewed as particularly helpful web-based resources to support exercise by people with MS (Casey et al., 2015). In another study comparing two groups of people with MS taking part in internet-based and control exercise interventions, 50% of the internet group were classed as non-adherent (recording less than 45% of recommended exercise sessions). The authors suggested that limited computer skills, and lack of contact with a therapist could have contributed to the reduced use of the web resource (Conroy et al., 2018). The current results suggest that participants may have had less interest or confidence in using web-based resources compared to paper-based resources to support them.

The information above refers to numbers of exercise sessions recorded across the different exercise types. Within the paper exercise diaries and as part of the interactive area on the Strong Steady Steps website, participants also had the opportunity to make additional comments. These allowed for daily and weekly reflection on performing the exercises in relation to their symptoms, as well as progress and future planning. These comments, although not suitable for detailed analyses, did provide some additional information regarding the experience of the participants as well as behavioural regulation techniques used in the current study. These comments revealed evidence for action planning (e.g., “Steps” exercise done on the cross trainer while watching Emmerdale on Tuesdays and Thursdays), as well as coping planning. The study was conducted in the summer of 2018, during which there was a period of particularly hot weather. As a result of this some participants described difficulties experienced with exercise due to worsening of symptoms in the heat. However, they also noted leaving exercises until the cooler evening time on particularly hot days to overcome this. Other examples of action and coping planning included saying no to other demands from family to prioritise exercise, and using a personal planner to create reminders to exercise on a set day and time. Exercise diaries were well-used, also showing that participants were monitoring their own progress. One diary charted the gradual increase in distance cycled on a home exercise bike from two miles in week one to ten miles in week twelve. Other feedback from the diaries (both paper and online) showed that some participants were doing more exercise than was required by the programme. This was especially true for “Steps” exercises, where two to three hours’ walking was noted on some days. Participants recorded walks carried out specifically for exercise, and also outside of their normal routine, e.g., when sightseeing on holiday. Other comments in the diaries related to participants being able to do more exercise without resting or holding onto a support, and increasing exercise time or number of repetitions, showing that they were making progress with their exercises. In sum, these comments showed some evidence of successful use of strategies, such as planning and self-monitoring of exercise progress in the current programme.

The study had a dropout rate of 50%, which is similar to other home exercise studies in MS. Mayo et al. (2020) had a dropout rate of 48% over three months and Conroy et al. (2018) 53% over six months. All three programmes had a similar weekly pattern of exercise. Mayo and colleagues (2020) advised participants to carry out their programme of combined exercise on most days of the week, including two “push days” for more intensive aerobic activity. Conroy et al. (2018) advised daily exercise which included core and lower limb strengthening as well as functional exercises. The Strong Steady Steps programme advised a total of six sessions each week to include strength, balance, and aerobic components. However, the high exercise requirement and high attrition common to all three suggest a possibility that participants may have dropped out due to being unable to meet the number of weekly sessions required. In the current study dropout was not explained by disability level, which did not differ between the completers and the dropouts (p=.61). A total of three or four sessions per week of a combination of strengthening and aerobic exercise have formed the basis of other programmes for people with MS (Learmonth et al., 2017b, Tallner et al., 2016). The former study was based on the MS guidelines (twice weekly strengthening and twice weekly aerobic exercise), with qualitative data from participants showing that this was seen as appropriate (Learmonth et al., 2019). Both Learmonth et al. (2017b) and Tallner et al. (2016) had attrition of 14% or below suggesting that lower exercise requirements may result in fewer dropouts. Qualitative data relating to the current programme may highlight issues relating to attrition, which could include perceptions of the weekly pattern of exercises.

After being given their exercise programme, current participants had a home visit at the end of week one, and a telephone call at the end of week four, but no other scheduled contact. Few participants used the opportunity to contact the researcher with questions. A review of studies of the modified versions of the Otago exercise programme in older adults found attrition rates from these programmes to be 23-30%. However, all the studies in this review had additional contact through home visits or centre-based supervised exercise. Other web-based programmes have also reported more regular contact with participants and lower dropout rates. For example, programmes with weekly or fortnightly contact via video chats or through an exercise website reported dropout rates of 20% or less (Donkers et al., 2020, Learmonth et al., 2017b). As well as answering participants' questions, these contacts were used to alter exercise programmes. However, video chats are an additional time commitment for the researcher, with one study reporting 96 minutes per participant spent on these calls (Learmonth et al., 2017b). In the current study with a single researcher, an approach of more limited contact was necessary. These results suggest that the combination of an exercise programme which demands a high frequency of self-directed participation, and limited support may have contributed to attrition in the current study. It may be that additional and more structured contact initiated by the researcher is necessary to support participation, particularly in those who may be new to exercising since their diagnosis of MS or following a change in symptoms.

7.4.2 EFFECTS OF THE INTERVENTION – PHYSICAL ACTIVITY

The changes in physical activity of either light or moderate to vigorous intensity for participants in this study were not significant. However, compared to other studies the level of pre-exercise moderate to vigorous intensity physical activity per day was higher for current participants at 32 minutes per day than the 18 minutes found in a recent review (Casey et al., 2018a). In addition to this mean pre-exercise step count for current participants was 4016 per day, which is lower than the 5840 found in the review (Casey et al., 2018a). This appears to be contradictory, and in addition step count did not increase as a result of the Strong Steady Steps programme. A possible explanation for this could be that several participants reported having home exercise equipment. Using an exercise bike or cross trainer may be a moderate/vigorous intensity activity which is not recorded as steps when an accelerometer is used for measurement. Participants in the current study did not increase accelerometer-measured moderate/vigorous intensity activity. This differs from other work with people with MS of a similar disability, in which moderate intensity step count was seen to increase by a mean of 900 steps per day (Mayo et al., 2020). However in this and other studies participants were given a way to monitor their own exercise intensity, being issued with a pedometer and advised to walk at 100 steps per minute, which correlates with moderate intensity exercise for people with MS (Learmonth et al., 2017b, Coote et al., 2014, Mayo et al., 2020). Enabling participants to monitor their own behaviour and the intensity of that behaviour with a pedometer has also resulted in increased self-reported physical activity (Hayes et al., 2017a). It may be that having a method of self-monitoring while exercising can more easily facilitate progression in both number of steps and intensity of activity.

7.4.3 EFFECTS OF THE INTERVENTION – FUNCTIONAL ABILITY

Overall there were no significant changes in functional ability as a result of taking part in the Strong Steady Steps programme. Balance-related outcomes in particular (Berg Balance Scale and Timed Up and Go) were expected to be improved by the "Steady" exercises. Walking measures (25ft Timed Walk and the subjective MS walking scale) were also expected to be improved by both the strengthening and aerobic components of the programme. These results differ from other combined exercise programmes. Improvements in Berg Balance scores with 60-90 minutes of class-based exercise done thrice weekly have been reported (Tarakci et al., 2013, Sangelaji et al., 2014). In contrast, increases in scores for balance and functional ability were not always reported following home-based exercises (Williams et al 2021, Conroy et al 2018). Therefore, it remains possible that more supervision is necessary to achieve these benefits. One way in which supervision can be advantageous is by encouraging participants to exercise with good technique and at an effective exercise dose. Current participants reported carrying out 1.4-2.0 sessions of "Steady" exercises per week. The online diaries recorded "Steady" exercise sessions lasting from 10-35 minutes over the twelve weeks, although the duration of sessions was not recorded by the 80% of participants using paper exercise diaries, suggesting the exercise sessions may not have been progressed as advised throughout the programme. There is also the possibility of poor exercise technique going uncorrected, making the programme less effective at achieving the functional goals. Previous work has also reported differences in training volume and intensity achieved between home and supervised exercise in MS. Guillamo et al. (2018) compared groups doing a high intensity aerobic programme either entirely home-based or as a combination of home and class-based exercise. The combined group significantly improved their 30-second sit-to-stand performance and VO_2 peak, while the home-based group did not, suggesting the intensity of exercise achieved at home was not sufficient to result in strength and fitness improvements. A review by Dalgas et al. (2008) also highlighted the uncertainty of both intensity of exercise and training volume, when carried out unsupervised. These results suggest the value of additional guidance and support for participants relating to achieving the right training volume and intensity at home, to achieve the targeted health outcomes. The high dropout rate from the Strong Steady Steps programme also meant that the small sample size reduced the power of the study to detect change in functional ability between the two groups.

7.4.4 EFFECTS OF THE INTERVENTION – WELLBEING MEASURES

The psychological subscale of the MSIS was the only outcome measure with a change in scores which was significantly different between the internet and control groups, with the internet group showing improved scores reflecting less psychological impact of MS after the intervention. The MSIS psychological subscale has items reflecting feelings of depression, anxiety, and fatigue. This suggests that although significant changes were not found in these individual outcomes, there may be an overall psychological benefit of the internet intervention compared to the control intervention. However, this significant finding should be treated with caution given the number of analyses conducted and this being the only significant between group difference. Additionally, only two participants reached the minimal clinically important difference of 8 points for this subscale (Cleanthous et al., 2017). Following the current exercise intervention Fatigue Severity Scale scores showed a small but non-significant decrease in both groups. Indeed only four participants met the minimal clinically important difference in Fatigue Severity Scale scores for people with MS of 0.45 points (Rooney et al., 2019a). Combined exercise studies have reported significant improvements in fatigue (Bahmani et al., 2019, Razazian et al., 2016, Grazioli et al., 2019), indeed meta-analyses showed that combined aerobic and resistance exercise programmes had the greatest effect on fatigue in MS (Safari et al., 2017). Given there were no other significant changes for measures of wellbeing in the Strong Steady Steps programme, more supervision of programmes may also ensure that exercise is sustained at the right intensity to achieve the wellbeing benefits.

7.4.5 EFFECTS OF THE INTERVENTION – BEHAVIOURAL REGULATION

The Strong Steady Steps exercise programme included a range of behaviour change elements, however the expected changes in the Planned Behaviour Questionnaire (PBQ) and Exercise Goal Setting Scale (EGSS) did not occur. This differs from other research, with similar baseline scores which has found increases in the EGSS following both an intervention to increase physical activity in MS (Motl et al., 2011) and a combined exercise programme with behaviour change support (Learmonth et al., 2017b). In line with both of these studies, there were also no other changes in behavioural regulation measures as a result of the Strong Steady Steps programme. However, in the current study there were significantly higher scores for the study completers in exercise goal setting and planning at baseline compared to the dropouts. Surprisingly significant improvements in exercise planning measured by the EGSS were not seen in the Strong Steady Steps programme, yet there was evidence in some exercise diaries of the use of planning skills. For example participants commented on action planning, such as increasing the challenge of a walk by reversing the direction to add more inclines. Coping planning was also shown through comments related to breaking up balance exercises throughout the day to manage fatigue. Another example given was walking to the park unaided but using a walking pole on the return journey when they were likely to feel more unsteady. Improvements in both exercise planning and goal setting were found in a study of exercise at the level of the MS guidelines supported by focused behaviour change support (Coote et al., 2017). Importantly these improvements were sustained at three month follow up showing the potential for the right input to have a longer-term impact on behavioural regulation. A recent review, which includes both cross sectional and intervention studies has shown positive associations between both goal setting and self-efficacy with both subjective and objective physical activity in people with MS (Casey et al., 2017). The changes were small in the current study, but suggest that baseline ability, and potential to develop skills in goal setting may be related to participation in and adherence to an exercise programme.

7.4.6 STRENGTHS

The study recruited people across a range of disability levels and those who provided data at both baseline and twelve weeks reported regular adherence to the programme. This demonstrates that the Strong Steady Steps exercise programme can be adapted to the needs of people with PDDS 0-7. Additionally, a strength of the study is the use of a combination of patient reported and objective outcome measures. Recent research into the use of outcome measures in MS across Europe has endorsed the use of a range of both therapist assessed and patient reported measures in line with requirements of the World Health Organisation's International Classification of Functioning Disability and Health (Rasova et al., 2020).

7.4.7 LIMITATIONS AND FUTURE RESEARCH

This study had a small number of participants providing data at both time points, with males underrepresented. Although females account for 72% of prevalent cases of MS (Mackenzie et al., 2014), they accounted for 93% of participants in this study. Missing data for some participants at the end of the study is also a potential source of bias. There were individual differences in the responses to the exercise programme, with some differences noted between those with higher and lower PDDS. However, the sample size did not allow for a detailed exploration of the heterogeneity of these responses as has recently been suggested (Baird and Motl, 2019). Another study limitation is the assessments and provision of ongoing support for participants being done by a single researcher. Assessor blinding was therefore not possible, however clinic-based assessments and home visits were conducted using a pre-determined protocol to ensure they were administered in the same way to each participant. The sustained effects of the programme beyond the end of the programme were not examined. Post-programme exercise participation and outcomes could be explored in future work. Future research could also include enhancement to the participant support, through either additional face to face sessions or remote methods of contact, in line with other studies. This small increase to exercise instructor or health professional time, may help to ensure exercise is being carried out at a suitable intensity and also help to address high participant attrition. It would also be useful to undertake a formal evaluation of the behaviour change aspects, including how they were utilised and participant satisfaction.

7.5. CONCLUSION

Both the internet and control arms of this intervention were successful in encouraging self-reported regular exercise participation in a group of people with MS across a range of disability levels over a 12-week period. The internet group improved significantly more than the control group in the psychological impact of MS, however many outcomes were assessed so this result may have been due to chance. The changes in other measures were not significant, but there were small improvements in balance, gait speed and fatigue. Other work has shown that greater improvements in these outcomes are possible with a higher intensity of exercise, which could be developed in future research. The current study also showed small improvements in exercise goal setting and perceived behavioural control. In order to develop this, future work could enhance the behaviour change support aspects of the intervention including the web-based materials and contact from the researcher in order to increase participation.

CHAPTER 8 – GENERAL DISCUSSION

8.1 SUMMARY OF THESIS FINDINGS

This thesis explored aspects related to sedentary behaviour, physical activity and exercise in people with Multiple Sclerosis (MS) using both quantitative and qualitative research methods. This final chapter will first report a summary of the main outcomes from each of the individual studies, followed by a broader discussion of topics which relate to different chapters of the thesis. This chapter will conclude with suggestions for future research.

8.1.1 CHAPTER 2 – COMPARISON OF SEDENTARY BEHAVIOUR QUESTIONNAIRES IN MS

This chapter investigated the use of a range of sedentary behaviour questionnaires for people with MS. Results confirmed previous research that self-reported sedentary behaviour is high in people with MS (11-13 hours per day). People with MS perceived the questionnaires as broadly suitable for people with MS, and questionnaires using a tick box format and clear layout were preferred. These questionnaires were subsequently used in the studies reported in chapters 6 and 7 of the thesis. Participants reported other sedentary behaviours not included in the questionnaires, and day to day variability of activities due to fluctuating symptoms. There was also variation in estimated sedentary time between questionnaires. Questionnaires show the types of sedentary activities which people engage in, while objective measures show overall patterns of activity in people with MS, therefore a combination of the two would provide good information about activity behaviours in future work.

8.1.2 CHAPTER 3 – PERSPECTIVES OF PEOPLE WITH MS ON EXERCISE BARRIERS AND FACILITATORS IN RELATION TO A PROPOSED EXERCISE PROGRAMME

In this chapter focus groups were conducted with people with MS around the topics of barriers and facilitators to exercise. An overarching theme of acceptance emerged from this data relating to accepting a diagnosis, lost abilities, and an altered future, and also being accepted into an MS specific exercise group. There were three organising themes: 1) “a very accepting atmosphere”, which encompassed the exercise environment and social support; 2) “future-proof, sustain and build”, which related to the effect of exercise on physical and mental health symptoms; and 3) “getting going and keeping going” in which participants discussed methods they used to motivate themselves to continue with exercise. Recommendations from this chapter included the need for knowledgeable health professionals and tailored support for participants to ensure exercises are done regularly and correctly. Exercise in an accepting environment was viewed as important, enabling participants to improve both physical and mental health. The social interaction of an accepting group of peers also served as a motivator.

8.1.3 CHAPTER 4 – PERSPECTIVES OF HEALTH PROFESSIONALS ON EXERCISE BARRIERS AND FACILITATORS IN RELATION TO A PROPOSED EXERCISE PROGRAMME

This chapter reported on focus groups around barriers and facilitators to exercise conducted with health professionals working with people with MS. The study revealed an overarching theme of communication, relating to how interactions between health professionals and people with MS impact on the provision and support of exercise. The organising themes were: 1)"coping alone and coming together", which related to the challenges of living with a diagnosis of MS, as well as the support offered by health professionals and peers, 2) "expectation creation", was focused on outcome expectations relating to exercise, 3)"push it", related to quality and quantity of exercise, and 4) "especially for you", which encompassed the need for personalisation of exercise programmes and support for people with MS. Overall recommendations were for improved multidisciplinary team communication, and also better communication between health professionals and people with MS around exercise. Based on these findings, it was concluded that training for health professionals to enhance their awareness of the body's response to exercise and knowledge of effective ways to support engagement and maintenance of exercise programmes is warranted.

8.1.4 CHAPTER 5 – INTEGRATION OF FINDINGS RELATING TO PERCEPTIONS ON A PROPOSED EXERCISE PROGRAMME OF PEOPLE WITH MS AND HEALTH PROFESSIONALS

This chapter included a wider discussion combining the findings of chapters 3 and 4, with a focus on the commonalities and relationships between the themes that emerged from the findings in people with MS and the findings from health professionals. More specifically, the interaction between acceptance and communication was discussed, suggesting that there is a need for health professionals to use communication which is appropriate to the patient's stage of acceptance. In addition, both MS patients and the health professionals acknowledged the value of social support from family and friends or via an MS group. Based on the reports of both people with MS and health professionals, the importance of building of strong therapeutic relationships between people with MS and health professionals and the availability of exercise choice were both seen as important. The provision of appropriate behaviour change support depending on the person's stage of acceptance, could also enhance participation. This support could include help with setting goals and ensuring goals are adhered to through action and coping planning.

8.1.5 CHAPTER 6 – ASSOCIATIONS BETWEEN PHYSICAL ACTIVITY, SEDENTARY BEHAVIOUR, AND MEASURES OF FUNCTION AND WELLBEING IN PEOPLE WITH MS

In this chapter, thirty people with MS took part in an assessment of objective and self-reported physical activity and sedentary behaviour as well as measures of function and wellbeing. Results showed that those with higher levels of moderate/vigorous physical activity (MVPA) and more daily steps, had better balance, faster walking speed, and a better self-reported assessment of walking ability. Less time spent in MVPA, fewer daily steps and more sitting was related to more severe MS disability. More physical activity and lower levels of sedentary behaviour were also associated with better scores for mental health outcomes. Those who were more sedentary had a slower walking speed. Higher self-reported physical activity was also associated with a higher predicted maximum workload from a submaximal VO_2 test. Differences in associations between self-reported and objectively measured outcomes with other outcomes were noted. For example, more objectively measured, but not subjectively measured sedentary behaviour was associated with higher depression. These findings study suggest the added value of conducting both objective and subjective assessments in people with MS, as each type of measure could reflect different aspects of activity or function. Objective assessments may not reflect the amount of effort put in for a functional activity, and the addition of a subjective measure shows how the performance of a task is perceived by the person.

8.1.6 CHAPTER 7 – A FEASIBILITY STUDY TO INVESTIGATE THE EFFECTS OF AN EXERCISE PROGRAMME ON PHYSICAL ACTIVITY, FUNCTION, WELLBEING AND BEHAVIOURAL REGULATION IN PEOPLE WITH MS

This chapter reported on a new 12-week home exercise programme consisting of strength, balance, and aerobic exercise. People with MS with a range of disability were recruited. All took part in the same exercise programme consisting of strengthening sessions for five lower limb muscle groups, a range of balance exercises in sitting or standing, and sessions of walking. Participants were asked to perform each of the three types of exercise at least twice weekly. The participants were divided into an internet group, with access to web-based resources to support their exercise programme and a control group, without access to these web resources. Among the fifteen participants for whom data was available pre- and post-intervention, adherence was good in both the internet and control groups. There was limited use of the website to record exercise. Core outcome measures of physical activity, functional ability, wellbeing, and behavioural regulation did not change significantly although there were small non-significant improvements in gait speed, balance and fatigue as well as exercise goal setting and planning. Results suggested that perhaps more contact and behaviour change support would have encouraged participants to exercise at a suitable intensity to achieve these benefits to health.

8.2 KEY TOPICS EMERGING FROM THE THESIS FINDINGS

8.2.1 MEASUREMENT OF OUTCOMES IN MS

Across the thesis a range of outcomes have been measured in relation to sedentary behaviour, physical activity, functional ability and wellbeing, including self-reported and therapist administered measures. Chapter 2 investigated perceptions of questionnaires used to quantify sedentary behaviour. This is in line with the need for people with MS to be involved in the evaluation of suitable outcome measures in order that the assessments can be more meaningful to them. In the cross-sectional study in chapter 6, where both subjective and objective measures were used, participants were seen to underestimate their sedentary behaviour by a mean of 2.75 hours per day. There were also differences in the associations between self-reported and device-measured sedentary behaviour with other outcomes. For example, objectively measured sedentary behaviour was associated with higher disability, but no such association was found for self-reported sitting time. The study also found differences in associations between subjective and objective measures of function with other measures. Faster gait was associated with more MVPA and steps, but not with self-reported physical activity or subjective walking measured by the MS Walking Scale. With research showing that the energy cost of walking can be higher for people with MS than the general population (Coote and O'Dwyer, 2014) people may be using more effort to achieve the same outcome. This supports the need for assessments of physical activity and sedentary behaviour, as well as functional outcomes to include subjective and objective methods. Questionnaires can highlight the context of the behaviour, specific activities, as well as perceptions of the behaviour and/or function, but may be subject to recall bias. Accuracy can be affected by cognitive and memory problems. The use of objective measures of sedentary behaviour and physical activity provide additional data on daily patterns of sedentary behaviour and physical activity, the intensity of periods of physical activity, or speed of functional activity such as gait. The two types of measurement together allow a more detailed picture of activity and how it impacts the individual.

In relation to this, the importance of measurement of specific outcomes in MS is now receiving attention in the published literature, with the World Health Organisation endorsing a combination of patient reported and clinician assessed outcomes to measure the domains of activity (functional activities such as walking) and participation (leisure and work-related activities) (Rasova et al., 2020). The study in chapter 6 used both self-reported and objectively assessed measures of walking: the MS Walking Scale (MSWS), Timed Up and Go (TUG), and 25ft timed walk. Indeed, a study of physiotherapy goal setting for people with MS across 26 European countries, showed walking was the most frequent outcome for which goals are set (Rasova et al., 2020), supporting the use of a walking measure as being functional and meaningful to participants. Walking measures are also easy to carry out and to monitor. In the Strong Steady Steps programme, participants were asked to set goals for increasing their duration and intensity of walking over the twelve week intervention. However, the speed-related objective outcome measures may not be linked to peoples' individualised goals. The TUG is recommended in exercise studies for people with MS, but more as a measure of muscle function and movement than of walking (Paul et al., 2014a). The same authors recommended the six-minute walk test to measure exercise tolerance (Paul et al., 2014a). This test records the distance walked over a six-minute period, giving a measure of walking endurance (Gijbels et al., 2010). A combination of subjective and objective measures of walking may be appropriate in MS. The MSWS reflects the person's perception of walking, whereas walking speed measures functional ability. The six-minute walk test, (or for those who cannot walk for six minutes, its two-minute equivalent), measures a different aspect of walking, walking endurance, and could therefore be another way to demonstrate functional improvement.

Muscle strength is another outcome which can be measured in MS, and can show progression as a result of an exercise programme. Muscle strengthening is part of the MS guidelines (Latimer-Cheung et al., 2013b), with previous research showing improvements in strength (Tallner et al., 2016) and fatigue (Sangelaji et al., 2014) as a result of resistance training. However perhaps of greater significance to participants are how the changes in muscle strength affect overall function. This was highlighted by the health professionals in chapter 4, who spoke of the need for clear communication to make patients aware of how an exercise such as a straight leg raise could make their sit to stand movement easier. This could assist with motivation in an exercise programme. Cross-sectional research has also found associations between strength in three lower limb muscle groups and performance in the six-minute walk test in MS (Mañago et al., 2018). Future work could investigate how strength improvements relate to measures of self-reported functional ability, such as the subjective MS Walking Scale and the physical subscale of the MSIS. This would give a clearer picture of the effect of an intervention on a person and the activities they view as important.

8.2.2 VOLUME AND INTENSITY OF EXERCISE

In chapter 7, results of the Strong Steady Steps exercise programme showed that participation in the programme was good across both the internet and control groups. Participants had increased their volume of walking, and the reflective comments showed evidence of progression in the "Strong" and "Steady" exercises. Despite this, at the end of the programme there were no significant changes in physical activity, strength or balance. This suggests participants were not exercising at the necessary intensity to achieve these benefits. In relation to exercise intensity, the health professionals focus groups in chapter 4, showed an awareness of the need for exercise to be challenging and for quality of exercise. This included the need to ensure movement is isolated to the correct muscle group, and related to functional activities. However in chapter 3, comments from people with MS suggested they were not always given the skills to assess and progress exercise intensity. Participants highlighted fluctuations in symptoms leading to inconsistency in both the amount of exercise carried out at home and how challenging the exercise was. People with MS also identified the need to ensure they were doing an exercise correctly, with examples provided of incorrectly exercised muscles. The qualitative data from both health professionals and people with MS showed that there was not a clear understanding of how challenging exercise needed to be, with greater emphasis on technique and relation to functional activity. Taking the findings from the different chapters together, they suggests that supervision of exercise, reinforcement of technique and the ability to assess and progress intensity could be needed as elements of an exercise programme.

In previous research, limited application of the theoretical principles of strength training was found in a qualitative study of physiotherapists working in stroke (Tole et al., 2020). The therapists questioned were seen to prioritise rehabilitation of function (e.g. sit to stand or walking) and participant enjoyment over ensuring effective strength training programmes. In the current programme, the exercises given were based on pre-intervention assessments of both function and strength, with the aim of increasing duration and intensity of all exercises and resulting in strength improvements. Information provided to participants in an illustrated booklet and verbally included how to increase the demands of each exercise by making sessions longer or increasing the resistance. However, after a week of exercises, some participants already highlighted small improvements in range of movement and strength which positively impacted their walking. It may be the case that in the current study, even though there was encouragement to progress to longer and more intense exercise sessions, these early functional gains could have prevented participants from seeing the need to work harder. Additionally, limited ongoing contact from the researcher did not reinforce the correct intensity of exercise. Therefore, this suggests that people with MS need to be given more specific support to assess and progress their exercise intensity.

Other research has highlighted the contribution of supervision at least in the initial stages of a programme (Dalgas et al., 2008) both for safety and for the monitoring of intensity. Other studies have provided participants with a pedometer and instructions to walk at 100 steps per minute, enabling them to monitor and potentially progress intensity themselves. These studies have been successful in increasing both the step count of the walking sessions (Learmonth et al., 2017b) and levels of daily moderate intensity activity (Mayo et al., 2020). Rated perceived exertion (RPE) was used in the cross-sectional study in chapter 6, and is a quick and easy method by which participants can be taught to assess their own exercise intensity. This is also proven to be a valid measure in MS (Cleland et al., 2016). RPE has also been used in other studies of combined exercise, where people with MS have been taught to assess the intensity of both aerobic and strength exercises (Tarakci et al., 2013, Tallner et al., 2016). Both studies resulted in improved functional ability with Tallner and colleagues (2016) also reporting increased knee extensor strength from their unsupervised programme. People with MS need to monitor their own exercise intensity, to permit exercise-related health benefits, but may need training and instruction as part of an exercise programme in order to do this.

8.2.3 SUCCESSFULLY SUPPORTING PEOPLE WITH MS TO EXERCISE

In chapter 5, the use of behaviour-related as well as outcome-focused exercise goals was recommended to support better communication between health professionals and people with MS. A systematic review of interventions to increase physical activity showed that behaviour-related goals were frequently used and that these were successful in increasing objective activity levels in people with MS (Sangelaji et al., 2016). A second review showed that a combination of behaviour and outcome-focused goals were used in a high proportion of studies and associated with successful interventions to increase self-reported physical activity (Casey et al., 2018b). The current study shows that these behaviour-related exercise goals should perhaps include some information about exercise intensity. This would encourage collaboration in the setting of goals which are SMART (specific, measureable, achievable, realistic and timed), which has been endorsed in MS (Khan et al., 2008). The process of listening to the person and creating goals together is also advocated to develop autonomy support, thus increasing motivation (Soundy et al., 2016). The inclusion of intensity in these exercise goals would also encourage therapists prescribing the exercises to have these more detailed discussions with patients and better equip them for self-monitoring.

As mentioned above, in order to encourage adherence to an exercise programme, with regard to both number of sessions and intensity of these sessions, support is needed. Other work has shown poorer adherence to unsupervised than supervised exercise, and better outcomes in relation to fitness and strength when the programme was either completely supervised or had elements of supervised exercise (Williams et al., 2021, Guillamó et al., 2018). During the current unsupervised programme, participants had just two scheduled meetings with the researcher, both within the first week. After this the only planned contact from the researcher was a telephone call at four weeks, with the responsibility of asking for assistance left to the participant. In contrast to this, a series of twelve-week web-based interventions to promote physical activity behaviour change in people with MS, used regular planned video calls to support participants. The calls had structured behaviour change content and followed a pre-determined schedule, being more frequent in the initial weeks (Dennett et al., 2018). A similar pattern of gradually reducing contact over the study period was followed in a combined unsupervised and supervised exercise programme, with behaviour change support incorporated into the supervised sessions (Carter et al., 2014). Results of both interventions showed high levels of participation with increased self-reported physical activity (Dennett et al., 2018) and exercise behaviours (Carter et al., 2014). However the latter intervention collected follow-up data six months after the programme ended, and found that physical activity had returned to pre-intervention levels. This shows that ongoing support and contact is necessary for these improvements to be maintained.

Where there is limited contact with the researchers, remote support via video calls or the internet has also been used to support exercise in other studies for people with MS. Two studies used regular video calls to supplement web-based resources with interactive content such as courses about maintaining an active lifestyle and people with MS discussing their participation in physical activity (Learmonth et al., 2017b, Motl et al., 2017b). This is in line with other research into the requirements of people with MS from web-based resources to support exercise. Key elements highlighted as important were interactivity and information stratified according to disability level (Sweet et al., 2013, Casey et al., 2015). The Strong Steady Steps exercise programme also offered web-based resources to support participants. The website included an area to plan and record individual goals as well as daily exercise sessions. There were fewer interactive elements than reported by other authors (Learmonth et al., 2017b, Motl et al., 2017b), which may explain the limited use of the website by participants in the current study. The study was conducted before the COVID-19 pandemic. However it has been highlighted that web-based methods are likely to be utilised more in the future where there may be a greater need for distancing in relation to exercise provision (Motl and Sandroff, 2020a). Web-based resources also offer the benefit of being able to reach large numbers of people. The continued involvement of people with MS in their development should ensure that they reflect the needs of this population.

Also relating to the use of technology, one study has found 104 MS-specific mobile phone applications (Salimzadeh et al., 2019), showing that there is demand for technology by people with MS to help manage their condition. The applications found were mainly focused on symptom tracking, raising awareness of the condition, and publicising MS-related conferences and meetings (Salimzadeh et al., 2019), with no applications dedicated to exercise for the management of MS. The development of a specific mobile phone application could be another way to support programmes of exercise. This would have the added benefit over a website of being able to directly issue exercise reminders and for people to record their goals, plans and progress more easily from any location. The application could also have a social networking area for participants to link with each other and the exercise instructors. Future work should continue to explore the needs of people with MS in relation to web-based and other technological resources as these can provide support for exercise as well as interaction with both the exercise instructors and other participants.

8.3 FUTURE RESEARCH

8.3.1 EXERCISE FOR THOSE WITH HIGHER DISABILITY

The current exercise guidelines for people with MS are for those with lower levels of disability due to the lack of research into exercise for those with greater impairments. Previous research has identified the need for more exercise-focused studies in the higher disability group (Edwards and Pilutti, 2017). Kalb et al. (2020) advocate a programme of suitable lifestyle physical activity for people with MS even when wheelchair dependent. A broad range of activities both sport/fitness and lifestyle related can be part of physical activity to meet the needs of those who are no longer ambulant. Studies have investigated adapted equipment such as recumbent steppers and treadmills with bodyweight support (Pilutti et al., 2016). In people with progressive MS and an EDSS of 6.0 – 8.0 both interventions reduced fatigue and improved health related quality of life (Pilutti et al., 2016). Other work has shown that a programme similar to Strong Steady Steps of combined strengthening, balance and aerobic exercise carried out over six months improved walking endurance in participants with a median PDDS of 4.0 with substantial mobility-related disability (Sandroff et al., 2017). Also applicable to those with higher disability (EDSS 6.5 – 8.0) a large-scale study has shown that regular home-based standing (supported by a standing frame), is well received by participants and improves quadriceps strength as well as both physical and psychological scores on the MSIS (Freeman et al., 2019). A feasibility study investigated the use of seated Pilates classes for people with MS who use a wheelchair, with promising results for sitting posture and balance, MSIS and pain (van der Linden et al., 2014). As well as providing exercise for more disabled individuals and those with progressive disease, there is also a call for exercise studies to address the changing needs of the ageing population with MS (Motl and Sandroff, 2020a) in order that options can be provided across the lifespan. Overall these results suggest that a range of exercise options can be made available to people with higher disability. Like other groups, preferences for both exercise type and setting should be considered when exercise is planned.

In chapter 3, people with MS mentioned the barriers to mainstream exercise environments for those using wheelchairs within the theme “a very accepting atmosphere”. There was discussion of the need for greater acceptance by exercise instructors regardless of physical ability. Other qualitative studies have had similar findings (Crank et al., 2017, Borkoles et al., 2008). The Strong Steady Steps programme included participants with PDDS scores of up to 7.0, using a wheelchair or scooter as their main form of mobility. Although higher disability did not exclude them from participating in the exercise programme, those who were more impaired could not safely use the cycle ergometer for the baseline fitness test. Exercise studies for those with higher disability therefore need to ensure that all equipment is accessible to those with physical impairments, or that assessments are based around functional activities which may be more meaningful to the person. Although research has shown that in MS, people with higher disability are less physically active, and as a result of this have different behavioural regulation needs (Streber et al., 2016), none of the studies referred to in the previous paragraph investigated the behaviour change support needs of people with higher disability when taking part in exercise. This is an important component of an exercise programme and could also form the basis for future work.

8.3.2 CHANGING SEDENTARY BEHAVIOUR

As well as future research into exercise, methods of changing physical activity behaviours have also been highlighted. Chapter 2 showed that self-reported sedentary behaviour is high in people with MS, and this is also true of device-measured sedentary behaviour (Jeng et al., 2019), particularly in those with higher disability levels (Ezeugwu et al., 2015b). A review suggested areas for future research should include correlates of sedentary behaviour in people with MS, which may include measures of behavioural regulation, as well as consequences of sedentary behaviour (Veldhuijzen van Zanten et al., 2016b). The review also highlighted the need for research into interventions which target a reduction in sedentary behaviour rather than a programme of exercise, which have also been endorsed as particularly relevant for people with mobility disability (Manns et al., 2012). Research is ongoing to investigate reducing sedentary behaviour as a suitable alternative or a precursor to exercise. This includes an intervention in two stages: firstly breaking up bouts of prolonged sitting, followed by additionally increasing daily steps (Aminian et al., 2019). Like the Strong Steady Steps programme this intervention is informed by a qualitative study of the opinions of people with MS (Aminian et al., 2017). The breaking up of sedentary time appears to be associated with better ability in functional activities in the general population (Sardinha et al., 2015), with the regular use of standing frames a promising intervention for people with higher disability from their MS (Freeman et al., 2019). However neither this study, nor the ongoing study by Aminian et al. (2019), includes any specific exercises or activities to be done in standing. Given the proven benefits of both breaking up sitting, and of regular periods of standing, it would be interesting to investigate whether a standing exercise programme, perhaps divided into short periods throughout the day, could achieve similar benefits.

8.4 CONCLUSION

Studies into changing activity behaviours in people with MS need to target a suitable range of subjective and objective outcomes, with a focus on key aspects which are important to people with MS and relate to function. Health professionals delivering these programmes need appropriate training to facilitate participants to develop the skills to plan, carry out and monitor exercise independently. This includes equipping people with MS with skills to exercise at the right intensity to achieve health outcomes, particularly now that many programmes are being delivered remotely. Web-based delivery of exercise is becoming more popular and should be another available option as well as investigating other technologies for exercise delivery, as this may be an increasing requirement in the future. Input from people with MS can help to support the development of resources to accompany exercise programmes that are accessible and relevant to them. Ongoing qualitative research with people with MS will support this, with the aim of providing suitable choice of exercise types relevant to the individual. These future priorities will aim to ensure exercise programmes for people with MS continue to evolve and meet the needs of this diverse group across the disease course.

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