Experiences of physical activity for people with multiple sclerosis in New Zealand

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Abstract

Being physically active is important for health, happiness, and longevity, however many people diagnosed with Multiple Sclerosis (MS) have difficulty continuing to be physically active. This narrative study draws upon the voices and insights of eight people with MS, of varied age, diagnosis, and mobility to understand their beliefs, thoughts, feelings, and motivations for physical activity. The research aims to investigate the lived experiences of physical activity of those who continue to be active and thereby inform how health professionals can better deliver programmes that support and facilitate greater levels of physical activity in those with MS. This study is underpinned by the conceptual framework of salutogenesis, which advocates a proactive orientation to health and focuses on factors that maintain health rather than those which reduce the risk of disease.

Interviews of the participants were analysed using reflexive thematic analysis and themes of knowing, meaning, managing, and enabling were identified. The themes illustrate why, and in what way, participants are physically active, and the various support systems they utilise to maintain levels of physical activity. The interviews revealed that those with MS are physically active in many ways, outside of any prescribed modality, and that the activities they undertake bring them confidence, pleasure, and an element of control over the course of their condition. The themes that have been identified can be used by health and exercise professionals as a guide to encourage conversations about physical activity and thereby promote, deliver, and support interventions that meet the needs and requirements of those with MS in New Zealand, while also enabling those with MS to understand, control and manage their own health outcomes.

Keywords: salutogenesis, reflexive thematic analysis, lived experience

CONTENTS

Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor used artificial intelligence tools or generative artificial intelligence tools (unless it is clearly stated, and referenced, along with the purpose of use), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signed

Debbie Skilton

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CHAPTER ONE - INTRODUCTION

Chronic illness, and its long-term management, is not linear. It is multifactorial, and no illness is more unpredictable in its presentation and progression than Multiple Sclerosis (MS). MS is a chronic neurological disorder that affects the myelin sheaths in the central nervous system. It has been widely considered to be an inflammatory autoimmune disease (where the body misdirects its immune system to attack its own tissue – in this case, the myelin sheath that protects the axons) but the cause of MS is still unknown (Murray, 2006).

According to the data produced by the MS International Federation, the prevalence of MS globally is 36 cases per every 100,000 people and is increasing(MS International Federation, 2020). The reasons for the increased incidence of MS are complex and there is no one clear hypothesis that either explains MS, or its increase, however the occurrence of MS at higher latitudes is growing (Stenager, 2019). Additionally, more females are diagnosed with MS on a global basis and there is regional variation as well, with the ratio of male to female incidence of MS varying between 1:2 to 1:4 depending in which region of the globe you live (MS International Federation, 2020). The most recent national governmental statistics follow the global trend for higher female incidence whereby, of the 2,896 people with MS living in New Zealand on census day 2006, 75% (2,176) were women and 25% (720) were men (Taylor et al., 2008).

MS is unique from other chronic debilitative disorders in two ways:

1. It primarily affects young people who are in their family and career-building years (the average age of a person with MS in New Zealand is 37 and globally is 30), with an incidence of around 134 diagnoses per year (1:1000 NZ estimated prevalence), and
2. It has an uncertain course, with disability occurring in a stepwise manner over many years (Alla et al., 2014; Multiple Sclerosis Society, 2024a; Ploughman, 2017).

People with MS often do not meet the Ministry of Health's recommended levels of physical activity (Ministry of Health, 2020) and physical activity declines over time as the disease progresses (Kayes et al., 2011). This means that, in addition to coping with a chronic degenerative illness over a long period, people with MS are at risk of an increased disease burden because of a sedentary lifestyle (Horton et al., 2015; Learmonth et al., 2019; Learmonth & Motl, 2016; Stennett et al., 2020).

MS is inherently unpredictable in its physical manifestation, even during a person's lifetime symptoms can change with several aspects of their mobility and cognition being affected at different times. This makes a planned exercise protocol, where a person would ordinarily see progress being made, increasingly unrewarding and frustrating for those with MS. By using narrative inquiry, we can begin to appreciate and understand the experience of MS as unique and as situated in the circumstances and social construct within which that individual lives (Sparkes & Smith, 2013). It is through the sharing of the lived experience of physical activity for those people diagnosed with MS, exploring the motivations and challenges they experience, we can obtain an insight into the meaning those people with MS attribute to physical activity and thereby inform how health and exercise professionals can support and promote long-term adherence to physical activity in this population.

Research Aim

This research evolved from a personal observation that there were people within my personal life with chronic illness that had experienced periods of relapse and remission, but who persevered with physical activity, notwithstanding the vagaries of their condition. While researching physical activity as a non-pharmacological intervention to mitigate inflammatory markers in metabolic syndrome as part of my postgraduate study, I happened upon studies that related to chronic illnesses such as MS. Despite not having any direct experience of anyone living with MS, I became curious about MS specifically as a diagnosis it affects young people, has an increasing prevalence in New Zealand and has an uncertain course with a gradual increase in disability over a long time. All the clinical research I had read related to specific exercise interventions for people with MS with measured results and outcomes, but there was no contextual understanding of the fluidity of symptoms of MS nor of the social and cultural factors that shape the reality of living with a diagnosis of MS. The focus of the extant research was on what exercise protocol would be best suited and, often, it involved an online intervention with exercises done alone at home.

It seemed to me there was a clear opportunity for physical activity to have a positive impact on those people with MS, improving both their symptom control and quality of life. More importantly, because MS is primarily diagnosed in the young, any successful physical activity intervention would have long-lasting benefits. However, to promote real-time regular uptake and the long-term adherence required, any physical activity intervention would need to be specifically tailored to the needs of those people with MS.

Therefore, this study investigates the motivations and everyday experiences of those with MS who are currently maintaining levels of physical activity of their own volition. The aim is to understand the rich personal experience of physical activity from the point of view of the person living with MS, within the environment in which they are situated and outside of any prescribed protocol. While MS is a chronic illness where those diagnosed experience an increase in disability as the disease course progresses, this study is not intended to be a disability study. It is an exploration of the experience of physical activity for people with MS guided by the Salutogenic model of health, which advocates a proactive orientation to wellness that focuses on health maintenance rather than on those factors that lower the risk of disease (Antonovsky, 1992). Within this framework, the research sought to capture information about positive physical activity experiences and habits rather than focusing on the barriers or difficulties. The insight and understanding of the positive steps taken by the participants will, in turn, inform and help exercise specialists to design, prescribe, promote, and deliver tailored physical activity programmes for those people with MS. It will also illustrate the support networks that meet the needs of those with MS, while also encouraging that person to maximise and gain control over their long-term health outcomes.

Thesis Structure

Chapter Two provides background and contextual information about MS and physical activity, including details about MS, the variations, and typical course of the disease following diagnosis. Following the background to MS is a literature review of the physical activity, health recommendations, and interventions for the general population and for those with MS, the motivations, and effects of physical activity for those with MS.

Chapter Three describes the conceptual framework of salutogenesis that underpins this study and how it influenced the research to obtain an insight into the resources are utilised by people with MS to continue to be physically active. Chapter Four expands on this and explains how the methodology upon which the study is based, and the research design facilitated the rich descriptive experiences that help to illustrate the reality of each participant and their relationship with physical activity.

Chapter Five discusses the practical aspects of the methodology and framework and the steps undertaken to give rigour to the research and validity to the lived experiences shared by the participants. The results of the interviews are summarised in Chapter Six, together with explanation of the themes that arose from the analysis of the transcripts.

The themes and the narratives that emerged from the data are contained in Chapter Seven. The way people with MS relate to physical activity, the reasons why they are active and the role it plays in their lives are discussed and what this informs us with respect to the current social narratives around physical activity and health. Recommendations on how health practitioners can support those with MS to continue to be physically active are contained in chapter eight together with the strengths and limitations of this study.

CHAPTER TWO - BACKGROUND AND CONTEXT

This chapter describes the etiology of MS and the different diagnoses and varied courses of the disease. Each diagnosis of MS impacts a person differently, depending on which type of MS they are diagnosed with, and even then, the disease course within each diagnosis can vary widely person to person and day to day. This chapter will define physical activity, the recommendations for daily activity promoted by governmental agencies, explain why engaging in and continuing physical activity is so important for people who are diagnosed with MS, and why many do not manage to maintain a regular pattern of routine exercise or physical activity. This background will provide context from which to explore the reasons why it is crucial to understand and appreciate the lived experience of those who continue to be physically active, despite the unpredictability of MS, and without following any structured or recommended exercise programme.

The Enigma of Multiple Sclerosis

The course of MS varies widely, with approximately 10% of people suffering mild symptoms over their lifetime (Primary Progressive MS) while around 85% of people with MS will suffer from Relapsing-Remitting MS (RRMS) that sees a slow worsening of disability over many months or years (Ploughman, 2017). Of those diagnosed with Relapsing Remitting MS, 40% go on to develop Secondary Progressive MS (Alla et al., 2016). This occurs when after several years with Relapsing-Remitting MS the clinical features of the disease change, and the progression of symptoms occurs at a more constant and predictable speed, without any relapse. Secondary Progressive MS has a similar rate of clinical deterioration as Primary Progressive MS and occurs within a similar age window (Lassmann et al., 2012). On average, a person with either form of MS will require a walking aid after 20 years. The innate difficulty with MS is that the progression of the disease is different for each person and the changes in physical capabilities are uncertain and require constant adaptation (Ploughman, 2017).

Due to early onset, slow progressive decline, and new drug therapies that reduce inflammatory lesions, there remains no cure for MS and people with MS can live with the disease for a long time. Barnard et al. (2020) suggests that the optimal management strategy for MS, as with many other chronic diseases, involves a combination of modern medication and lifestyle risk-factor modification. While first-line immune-modulating drugs have resulted in a modest reduction in MS relapse rates, there remains a question of the cost-effectiveness of such therapies given the long-term use that is necessitated, the side effects and the potential for adverse events (Barnard et al., 2020). It is therefore essential that we develop and evaluate interventions that reduce symptoms and improve the quality of life for people living with MS. Previously it was thought that exercise may exacerbate symptoms of MS; however, there is now an increasing body of evidence to suggest that it is not only safe but also effective at many levels (Clarke & Coote, 2015).

In fact, those who age most successfully with MS are those who look after their health – they exercise more, smoke less and drink less alcohol than other people of their age without MS (Ploughman, 2017). For those people with MS, exercise also has the additional benefit of improving brain health (promoting synaptic growth, angiogenesis, and neurogenesis), as well as promoting muscular strength, reducing metabolic risk factors and markers of inflammation, improving functional capability, independence, and quality of life (Carling et al., 2018; Learmonth et al., 2019; Ploughman, 2017). Conversely, a lack of physical activity exacerbates secondary impairments such as muscle weakness, metabolic dysregulation, and low cardiovascular fitness (Learmonth et al., 2019; Sangelaji et al., 2017).

A systematic review by Huynh et al. in 2021 found that being physically active may also help people diagnosed with MS to develop a reserve that allows them to withstand disease manifestations and impairments. Co-morbidities such as hypertension, heart disease, hypercholesterolemia, peripheral vascular disease, and diabetes have negatively impacted disability progression rate in those people with MS. These conditions often develop early in adulthood because of inadequate engagement in healthy lifestyle behaviours. The review authors opined that there may be a critical, yet overlooked, opportunity to deliver lifestyle-type interventions in the early stages of MS, as interventions might be more readily adopted at that stage of diagnosis and promote a reserve capacity, and/or mitigate comorbid conditions with long-term implications for MS (Huynh et al., 2021).

The Ministry of Health recommends that all people engage in a certain amount of physical activity and avoid sedentary behaviours (Ministry of Health, 2020). However, studies show that fewer than 20% of those with MS are meeting public health recommended levels of physical activity (Learmonth & Motl, 2016) and that 78% of people with MS are sedentary compared to 38% of the general population (Horton et al., 2015). Furthermore, people with MS are less likely to engage in a form of physical exercise compared to both the general population and to people with non-chronic disease clinical populations (Kinnett-Hopkins et al., 2017). The perpetual cycle of decline in mobility and activity leads to progressive deterioration in function for those with MS and a real risk of secondary adverse health conditions, such as obesity, diabetes, and cardiovascular disease (Backus, 2016; Christensen et al., 2016; Kalb et al., 2020; Sikes et al., 2019). This is further evidenced in a study by Jeng et al. (2021), which found that those people with MS of an older age, or with progressive MS, and higher disability status spend prolonged, uninterrupted periods being sedentary. The view of the authors is that the aim is to have a behavioural intervention that breaks the pattern of sedentary behaviours throughout the course of the diagnosis to prevent the secondary consequences of inactivity (Jeng et al., 2021).

Unfortunately, because of physical limitations, many individuals avoid physical activity after diagnosis and only a small number of individuals with MS meet the recommended guidelines set by governmental agencies; additionally, the less ambulatory the individual, the less likely they are to participate in a form of physical activity. The problematic nature of this juxtaposition of physical activity and mobility suggests an inactivity cycle that propagates itself whereby the individual is physically inactive because they have limited mobility and the lack of physical activity further exacerbates the reduction of mobility (Fasczewski & Gill, 2017).

Physical Activity recommendations for MS

The Multiple Sclerosis Society New Zealand (MSNZ) recommends that those with MS partake in regular exercise as has been discussed above, it has specific benefits to help them to stay mobile and for symptom management as MS progresses. MSNZ advises that an exercise programme can assist with fatigue, bone strengthening and weight management (the latter two maladies being side effects of steroid medications prescribed for MS) and recommends following the public health guidance (Multiple Sclerosis Society, 2024b; Multiple Sclerosis Trust).

To that end, the New Zealand Ministry of Health promotes two exercise programmes for the general health and wellbeing of the New Zealand population. The first of these is the Green Prescription (GPx), which was instituted in late 1997 by the Hillary Commission. The focus was aimed at those people with illness conditions (such as heart disease and hypertension) who were under the care of their General Practitioner (GP) and who were largely sedentary, with physical activity likely to be an important part of their health management programme. It was envisioned that the GP would assess the patient during a GP appointment and take approximately 5 minutes to prepare and prescribe a home-based moderate health activity for the patient to follow. The GPx, which combined with the public health recommendations for the number of minutes and sessions per week that constitute minimum health requirements, was hoped to increase activity levels of those with specific illness conditions and who were socio-economically disadvantaged(Pringle, 1998).

The second exercise programme promoted by the Ministry of Health is a time-based recommendation of at least 2 ½ hours of moderate or 1 ¼ hours of vigorous physical activity spread throughout the week (Ministry of Health, 2020). This recommendation is based on a 1995 study by Pate et al. for the Centers for Disease Control and Prevention (CDCP) and the American College of Sports Medicine. This 1995 study recommended that health organisations and educational institutions clearly communicate a regular exercise prescription to the United States public that would outline the amounts and types of physical activity required to promote a healthy lifestyle and prevent illness. The recommendation was that every US adult should accumulate 30 minutes or more of moderate-intensity physical activity on, preferably, every day of the week, and suggests this can be accumulated in short bouts. Furthermore, the physical activity recommended in this 1995 study by the CDCP was not a structured or planned exercise or fitness regime, but rather promoted the concept of physical activity as being any bodily movement produced by skeletal muscles that results in energy expenditure (Caspersen et al., 1985; Pate et al., 1995).

As there is no specific advice or recommendations on the level of intensity, duration, or adaptation of physical activity for those with MS, it can be assumed that the general Ministry of Health recommendations referred to above apply. Advice from the National Multiple Sclerosis Society in the United States (Kalb et al., 2020) offers recommendations as to physical activity level requirements for those with MS, specifically considering all the barriers and facilitators experienced by people with MS throughout the course of the disease. The analysis by Kalb et al. (2020) considers physical activity (including lifestyle physical activity) and exercise as defined by Casperson et al. (1985) as being distinct from rehabilitation exercise. The paper by Kalb et al. (2020) distinguishes rehabilitation exercise from physical activity as rehabilitation is strictly intermittent to regain or maintain physical function, promote functional independence, prevent complications of dis-ease, and make an improvement to quality of life, and as such is not to be continued on a long-term basis.

The cumulative evidence from the meta-analysis by Motl et al., suggests that individuals with MS engage in less physical activity than the general non-diseased population (Motl et al., 2005). The magnitude of the difference compared with non-diseased populations was significant (approaching 1 SD); the relatively inactive lifestyle of individuals with MS is alarming given the generally accepted prevalence of physical inactivity and sedentariness among adults in the USA. This concern is exacerbated by the association of sedentary behaviour with an increased relative risk of cardiovascular diseases, type-II diabetes, and obesity in the general population and likewise in those with MS. Increasing the activity levels of those with MS, although potentially challenging, is crucial for long-term health in this population (Motl et al., 2005). Motl's paper further finds physical activity differences dependent on both the type of MS (with primary progressive showing even lower levels of physical activity) and the gender of the person diagnosed (with combined samples of men and women being less active than samples of women alone). It is opined in the study that to target appropriate physical activity promotions to the MS population then further research is needed to break down the diagnoses and gender differences in levels of activity, as well as to identify the correlates of physical activity among those with MS (Motl et al., 2005).

For instance, to increase the levels of physical activity in those people with MS, a paper by Kalb et al. (2020) proposes a shift from exercise training for fitness toward a focus on lifestyle physical activity. Lifestyle physical activity is defined as a daily accumulation of 30 minutes of moderate activity per day. Options for lifestyle physical activity for those with MS include walking, gardening, road cycling, hiking with poles, individual and team sports, and dancing. If individuals with MS are unable to meet recommended levels of physical activity or are not confident in doing so, it is proposed that the alternative lifestyle physical activity recommendations may help increase daily movement (Kalb et al., 2020).

Despite the increasing evidence of the benefit of physical activity for people with MS, an updated meta-analysis by Kinnett-Hopkins et al. (2017) failed to find any change in physical activity levels in the last decade. The evidence suggests that persons with MS continue to engage in lower levels of physical activity than non-diseased populations despite being aware of the benefits. A new finding of this meta-analysis is that the physical activity levels of the MS population mirror those of other chronic disease populations. However, those people with MS remain less physically active than those with clinical conditions that result in similar levels of disability (such as spinal cord injury or stroke).

The authors in that study propose that pragmatic longitudinal effectiveness trials need to be developed to qualitatively assess the reasons why some individuals adhere to the physical activity guidelines and trials and why some do not. This would assist in developing strategies to overcome physical activity participation barriers (Kinnett-Hopkins et al., 2017).

The meta-analysis by Kinnett-Hopkins et al. (2017) illustrates an important distinction that may provide insight into the common barriers to physical activity across different populations. MS is unique in that it is both a chronic disease and a condition that can result in similar disabilities to clinical conditions such as stroke; however, having a diagnosis of MS results in a larger decline in physical activity than these similar clinical populations. This evidence highlights that, despite the efforts made over the past decade, persons with MS are still not engaging in sufficient levels of physical activity. There is a factor in the aetiology of MS which intercedes with and impedes those with MS diagnosis from partaking in the benefits of physical activity.

Exercise vs Physical Activity

The studies and current literature discussed herewith use the terms physical activity and exercise interchangeably. The difference between these terms is discussed in Ploughman (2017) where physical activity is referred to as any activity where the body is moving, whereas exercise is a planned and structured subcategory of that physical activity (Caspersen et al., 1985). For people with a disability some types of physical activity, such as chores and walking outdoors, are challenging enough to be considered a form of exercise. However, the distinction between the two terms is important, as participation in a structured exercise programme can see an improvement in levels of physical activity for those with MS (Horton et al., 2015).

However, despite the positive outcomes for those with MS there is a low level of continued engagement in exercise and similarly, participation in physical activity studies concerning MS is also low. Quantitative or feasibility studies in this area have high attrition (upward of 85%) impacting research quality; the reason for this has not yet been explored (Learmonth et al., 2019). Qualitative research into the reasons why people with MS are reluctant to engage in or adhere to physical activity or exercise programmes (even as part of a study) would assist in the provision of clinical support mechanisms specifically tailored to the needs and challenges of those people with MS.

There have been several mixed method studies conducted to determine the barriers and facilitators to exercise participation in those with MS through qualitative patient feedback as an adjunct to quantitative testing. It is evident in the studies that exercise is important and can provide positive outcomes for those who have MS. Some examples of exercise interventions studied include web-based physiotherapy programmes over a 12-week period (Sangelaji et al., 2017; Sangelaji et al., 2016; Smith et al., 2013), a 12-week in-person group exercise class (Learmonth et al., 2013), a home exercise programme (Plow et al., 2009) and a balance exercise programme for those with limited mobility through a physiotherapist led group exercise programme (Carling et al., 2018). These were all mixed-method studies that used questionnaires and focus groups to obtain qualitative post-intervention feedback from study participants. In addition, a recent study by Stennent et al. (2020) interviewed participants in one-on-one in-depth semi-structured interviews in a community dwelling and found that people with multiple sclerosis held a multidimensional and complex view of exercise and physical activity.

Several themes were identified in the qualitative findings in these mixed methods studies. The online exercise programme became boring and did not motivate those in the proof-of-concept study for the Blue Prescription intervention(Sangelaji et al., 2017), nor did it provide the education or support that personalised, adaptive programmes could – such as that in a 12 week in-person group exercise class(Learmonth et al., 2013). This theme of support is reflected in the qualitative meta-synthesis conducted by Christensen et al. (2016), where social factors, professional support, a customised programme and relationship with the physiotherapist and the management of outcome expectations (e.g., fatigue, symptom fluctuation, slow and steady benefit, and improvement) were facilitators to exercise in those with MS. More recently, a qualitative study, embedded within a randomized controlled trial testing the implementation of the Canadian Physical Activity Guidelines for Adults with MS, found that there were many positive outcomes beyond the physical benefits of being active. These included increased confidence, connectedness, improved mental health and emotional well-being(Akbar et al., 2022). It is more than just increasing fitness that motivates participation in physical activity in those people with MS.

The effect of exercise on the spousal relationship was explored in the qualitative study by Horton et al. (2015). In this study the maintenance of personal independence, improvement of physical functions, and improvement of psychological outlook, perceived quality of life, and the social aspects were found to be facilitators to adherence to exercise for those people with MS. This study also assessed the impact of an exercise programme on the spouse of a person with MS. From the point of view of the spouse, it was evident that an important facilitator to become involved in an exercise programme was the independence gained for both partners. For the most part, the improved physical function experienced because of exercise, and the resultant ability to self-care, relieved the spouse from the role of caregiver.

Whilst social connectivity, support and personally adapted activities facilitated exercise, the mobility issues experienced to attend group sessions outside the home were a considerable barrier, along with the transient effects of fatigue on a person with MS. The study by Horton et al. (2015) describes the fatigue barrier as being like an opportunity cost, with energy being a limited resource for a person with MS. If the energy is used up getting to and attending an exercise class, then there is little energy left for other activities, such as weekly chores. This barrier can be alleviated or offset by the management of the impact of the exercise by the professionals involved. This allows the person with MS to cope with both the outside energy demands and the progressive nature of the disease(Carling et al., 2018; Learmonth et al., 2013; Stennett et al., 2020).

Mobility and fatigue are, in many respects, interrelated and complex for a person with MS. As a person's physical infirmity increases, then mobility (and fatigue) becomes more of an issue due to both physiological and pathological factors (Smith et al., 2013). The difficulty and challenges involved with the lack of freedom of bodily movement are multi-faceted and a participant in the Stennett et al. (2020) study refers to being unable to walk or use public transport, necessitating further sedentary behaviour by the requirement to drive everywhere. The spiraling nature and sense of loss of control are tied into the freedom of movement and illustrate how important the maintenance of physical strength and activity is to those people with MS. Interestingly, a qualitative study of highly active people with MS found that those participants who continued with physical activity enjoyed the nourishment of social connections through exercise, did not put any focus on their limitations, but instead focused on what they could achieve. The participants made very sure they worked within the limits of their energy reserves, adapting or changing the chosen activity as required (Fasczewski et al., 2018). These findings suggest that, if motivation, expectation, and energy levels are managed carefully then there are real benefits to exercise for those with MS.

While mixed methods and qualitative studies highlight the barriers and the facilitators of activity, such a "snapshot" of experience does not reflect the complexity of an MS diagnosis and the evolving and flexible relationship a person diagnosed with MS has to physical activity as the disease progresses. To that end, narrative inquiry can be a way of building an understanding of how people diagnosed with MS make sense of their life and their relationship with physical activity. While there has been narrative exploration with respect to the perception of exercise amongst those with MS and how it has evolved over time(Richardson et al., 2019), exploration of environmental influence on exercise experiences for those with MS (Richardson et al., 2022),a case study of a paralympic Gold Medalist (Kean et al., 2018), a narrative evaluation of a balance intervention (Carling et al., 2018) and an insight into the impairments and bodily experiences of those people with MS (Borkoles et al., 2008). Understanding the meaning behind being physically active is crucial if it is to be promoted successfully to those with MS, and to ensure that the appropriate kind of support is there to encourage those people to adapt and evolve activities as their symptoms fluctuate.

Similarly narratives have been used with respect to physical activity promotion and maintenance in spinal cord injured (SCI) populations, and the study by Papathomas et al. (2015) uses narratives to explain what motivates those with SCI to become, and stay, physically active. The narratives therein aid understanding and provide a starting point for health practitioners to facilitate behaviour change interventions for those people with SCI who are not motivated to be physically active. The Papathomas et al. (2015) study is specifically related to loss of mobility due to a traumatic force or experience. In contrast MS is a gradual and fluctuating loss of mobility over an indeterminate time and the experience of physical activity for a person diagnosed with MS is uncertain and complex. A narrative reflecting the meaning persons with MS ascribe to being physically active would be useful to inform and give context to the physical activity interventions which are aimed at those with MS (Richardson et al., 2019).

MS-specific physical activity intervention in NZ

The feasibility of a Blue Prescription (BP) to engage people with MS in regular physical activity along the lines of the current Green Prescription promoted by the Ministry of Health (Health New Zealand, 2024) has been studied in both metropolitan and rural scenarios. A qualitative study followed the pilot intervention of the research undertaken to assess the BP concept in a metropolitan situation (Smith et al., 2013) and a similar, albeit smaller, mixed-method study was undertaken to assess a web-based provision of the BP in a home setting for rural purposes(Sangelaji et al., 2017).

The metropolitan study mentioned above encompassed personal home visits by the physiotherapist supplemented by online, text or phone contact, and found that the companionship and support of a physiotherapist was an important factor and key theme in the adoption of and engagement in physical activity and behavioural change. The BP approach was found to be supportive, motivating and enabling but required further refinement, specifically regarding the method of communication, tools for measuring success and the consideration of additional motivation through an exercise buddy system(Smith et al., 2013). Conversely, the findings of the rural web-based programme showed that the participants found their motivation to exercise waned over the 12 weeks due to the online provision, the lack of social support, and the isolated nature of the telerehabilitation method(Sangelaji et al., 2017).

Collectively, the findings of the BP focused qualitative studies illustrate that support is an overarching theme for a successful physical activity intervention, and that support includes professional therapeutic systems, assessment and evaluation of goals and achievement with the movement towards self-motivation being the primary goal of the programme. The New Zealand experience reflects themes identified in other overseas studies from the UK and US environments, but further research is required to assess whether similar themes occur across a broader range of countries and cultures. Furthermore, the participant numbers are small (the rural study referred to above consisted of four participants) and those who take part in these studies are generally motivated or interested in improving their level of physical activity, so may not reflect the general population of those people with MS.

The literature reviewed emphasises that the majority of those people with MS do not engage in adequate levels of physical activity to ameliorate any secondary illnesses resulting from sedentary behaviour. A key benefit to exercise for those with MS is that the ability to self-care is retained (or regained) and both independence and quality of life are maximised for as long as possible. This is important given that MS is primarily diagnosed in the young and has an unpredictable and unknown progression. Qualitative research to date suggests that social support, personal connection and professional adaptive advice and exercise prescription facilitate adherence to physical activity programmes for those people with MS. The presence of these factors in an intervention may ensure that the person with MS is supported in the exercise programme at an appropriate level with the opportunity for group interaction with those who have similar challenges, and the secondary barriers of fatigue and expectation of outcome are managed or eliminated. Global themes and results are reflected in the New Zealand context through the Blue Prescription pilot study with areas for refinement for both the provision of in-person and the online interventions arising as a result. The NZ studies, which incorporated qualitative feedback from those with MS, are working towards a programme that will eventually support those diagnosed with MS in New Zealand to identify and overcome the barriers to physical activity and reap the rewards of a more active lifestyle.

Encouraging long term adherence to physical activity

Discovering the physical activity levels of those with MS, rather than relying on evidence from the general adult population, is important because both the variable symptoms of MS and recommendations to those with MS by clinicians to 'take it easy' may pose a substantial barrier to being physically active. Similarly, relying on the recommendations for physical activity levels of those of the general population may be too onerous at certain times during the disease course for those with MS. Relying on recommendations for the general population may well result in reduced physical activity levels for individuals with MS, particularly when compared with adults without any disease(Motl et al., 2005). The right level of advice and support is needed, tailored to the lived experience of those diagnosed with MS.

Governmental advice aimed at reducing sedentary behaviour and increasing physical activity for the general population with the advent of minimal requirements of physical activity per day, every day, has been a public health initiative for almost 25 years. However, a consistent finding is that even while these measures are useful for encouraging exercise initiation, there is actually little evidence supporting long-term change in physical activity behaviours or beneficial effects because of these initiatives in the general population (Handcock & Jenkins, 2003; Lind et al., 2009; Pringle, 1998; Williams et al., 2012; Williams et al., 2017) This plateau is also evident in the data produced by the Ministry of Health annual survey where levels of inactivity in the adult population remain at 50%, where they were when the activity measures were first introduced(Ministry of Health, 2019).

Therefore, rates of physical inactivity for the general population in NZ remain high despite the well-publicised health benefits that result from being physically active. Studies have found that dropout rates and non-compliance with physical activity recommendations are major contributors to physical inactivity in the general population(Lind et al., 2009). Attempts to understand and increase physical activity behaviour have traditionally been guided by theories that emphasise cognitive factors (the way we think) rather than the way we feel. However, core affective valence in response to physical activity has been suggested as an important factor in determining whether a person will consider future physical activity behaviours(Williams et al., 2012).

How a person feels about and reacts to physical activity is complex, and this applies even more so when you live with a chronic condition that is, in and of itself, complex. The difficulty with the imposition of an exercise or physical activity programme is that when physical exertion is initiated (particularly after a long period of inactivity, or as a beginner) a person is likely to have a low level of fitness and/or a potentially high body weight. As a result, unless managed correctly, they will experience adverse perceptions of exertion, discomfort and physiological stress which make the experience unpleasant, and this is a contributor to high dropout rates(Lind et al., 2009; Williams et al., 2012). A quantitative study looking at affective response during exercise found that there was an association between affective response and physical activity behaviours. The authors suggest that if the feelings experienced during physical activity could be made more positive (equivalent to a one-unit increase in the feeling scale) this would result in an increase of between 15 and 29 minutes per week of participation (Williams et al., 2012). Preliminary indications in the study by Williams et al. suggest that self-paced physical activity along with modality, physical and social settings and mindfulness strategies may be factors that lead to a more positive response to exercise.

There is a similar observation made in the comprehensive systematic review by Lind, et al. which looks at affective response, cognitive response and the use of association and disassociation to overcome the discomforts of exercise by moderating exercise intensity(Lind et al., 2009). Whilst these strategies are useful in the toolbox to improve the exercise experience, it seems that physical activity is still being considered a chore or task to be endured to adhere to public health guidelines. Masking the perceived discomfiture of exercise does not appear to address or improve the way we perceive physical activity itself and the positive rewards that can flow from it.

To conclude, physical activity that was initially recommended to be unstructured has become structured through the recommendations of time, intensity and modality. Studies suggest that individuals have lost the art of moving for enjoyment and physical activity has become a chore, a task, intense, overly formal and medicalised. Given that adherence to an exercise prescription for physical activity for the MS population is so low despite specific interventions such as the Blue Prescription, and with strict adherence to the Ministry of Health Activity Guidelines for the general population being problematic, there is an opportunity for health care professionals to be proactive and emphasise the positive feeling of bodily movement, thereby facilitating more activity in all those who are challenged by current health promotion protocols. The opportunity to learn from those people with MS who are positive about and enjoy being physically active over the long term can, without doubt, be advantageous to those who support those with progressive diseases such as MS who find it more challenging to move regularly. As a result, and to facilitate the sharing of these experiences, this study is guided and influenced by a Salutogenic model of health promotion which is discussed in the following chapter.

CHAPTER THREE – THEORETICAL UNDERPINNING

This chapter describes the conceptual framework which underpins this study of the role physical activity plays in the lives of people with MS and how those with MS facilitate their continued participation in physical activities. MS by its very nature is fluid for a person, both over the course of the diagnosis and in the ways, it presents itself, the symptoms experienced, the timing and the physical impact those symptoms have. MS is an enigma, and the experience of MS is different for each person diagnosed and the impact on a person's life day to day is unpredictable in its progression. This study investigates the everyday experiences of those with MS who are currently maintaining levels of physical activity of their own volition to understand the rich personal experience of physical activity from the point of view of the person living with MS, within the environment in which they are situated and outside of any prescribed protocol. The next part of this chapter will outline the concept of salutogenesis, a positive model of health promotion that appreciates the ebb and flow of health and disease over the course of a person's life and how this philosophy influences the present study.

Salutogenesis

This research is guided by Antonovsky's salutogenic model of health which sees each of us, at a point in time, as being on a continuum or axis between total ill-health (dis-ease) and total health (ease). In this way, the salutogenic model of health promotion advocates a proactive orientation to health and focuses on factors that maintain health rather than on factors that lower the risk of disease(Antonovsky, 1993). Naturally, any research that is influenced by the principles of salutogenesis will therefore look at what moves people toward the health end of the axis, from wherever they may sit on the continuum. Furthermore, salutogenesis provides a framework for seeing the entire person, and thereby examining and understanding the relationship between that individual and the world that they occupy(Antonovsky, 1996; Eriksson & Lindström, 2005). This understanding of the world of those who live with MS, with its unique and unpredictable nature, is important as their experiences cannot be so easily generalised to a "norm". This view represents a paradigm shift away from pathogenesis, which focuses on risk factors for disease, toward salutogenesis which focuses on the strengths and determinants of health, a concept introduced by Antonovsky after the publication of his book in 1987(Antonovsky, 1987). In essence, rather than looking at why people became ill, Antonovsky instead asked, why do people stay healthy?(Becker et al., 2010).

Traditionally, the concept of pathogenesis has been the theoretical framework for most health research and practice in the Western world. In a formal sense, the concept of pathogenesis is defined as the study of disease origins and causes and from that starting point looking backwards to determine how individuals can take steps to avoid, manage, or eliminate that disease or infirmity. In contrast, salutogenesis, which encompasses the study of health origins and causes, starts by considering an individual's health and looks forward at the factors that can create, enhance and improve the physical, mental and social well-being of that person(Becker et al., 2010).

Antonovsky (1987) developed this view as a result of his epidemiological studies on menopausal women in Israel, a study which happened to include participants who were survivors of the holocaust. In these studies, Antonovsky found that despite the stress created by and endured through the holocaust, these survivors not only recovered and survived, but they thrived. In explaining this phenomenon, Antonovsky proposed that there must be health-causing factors involved. It was in this search for the human factors that were characterized in these survivors that Antonovsky came to the salutogenesis model. The salutogenesis model proposes that the goal of health research should be to identify, define, and describe factors that cause positive health to supplement and enhance our knowledge about how to prevent, treat, and manage negative health (pathogenesis). Both models of health promotion are synergistic and complementary in that the salutogenic framework focuses on discovering the causes and precursors of health and identifying health or salutary factors, whereas, pathogenesis focuses on discovering the causes and precursors of disease and identifying disease risk factors(Becker et al., 2010; Eriksson & Lindström, 2005).

Interestingly, the concept of salutogenesis has long been reflected in the World Health Organization's (WHO) definition of health. The constitution of the WHO states that preserving health requires a holistic approach in that "health is a complete state of physical, mental, and social well-being and not merely the absence of disease and infirmity"(World Health Organization, 1946). Antonovsky believed that salutogenesis should become the theoretical basis for developing, testing, and implementing plans and practices that enhance health and well-being(Antonovsky, 1993). This narrative study is therefore influenced by the concept of salutogenesis and is appropriate to elicit the positive factors that keep people with MS involved in physical activity. This is especially important when uptake and adherence to physical activity is so low in those with MS(Motl et al., 2005). Those people with MS who keep active are (seemingly) in the minority, and there appears to be no evidence of any in-depth studies of the positive factors that encourage ongoing participation in physical activity. The purpose of this study, therefore, is to add to existing knowledge by investigating the rich personal experiences of people with MS who are currently physically active of their own volition to understand the positive steps they take to remain physically active, within the context in which they live. The findings of this study can, in turn, ideally inform exercise professionals and clinicians as to how physical activity can be better promoted to those with MS, thereby ensuring greater uptake, improving long term adherence, and obtaining better overall health outcomes.

Antonovsky (1987) suggested three specific ways for salutogenesis to guide research: firstly, the data needs to be looked at with a different lens. For example, look at the people who are succeeding and find out why they are doing well, instead of looking into the reasons why people fail. Secondly, the researcher should ask the participant about the factors related to their success, not just the factors related to the problems or barriers they have encountered; and finally, the researcher must be open to considering alternate hypotheses to explain the outcomes. Finding practices that promote and develop positive health outcomes could then sit contemporaneously with pathogenic practices to create an environment that nurtures, supports, and facilitates optimal well-being(Becker et al., 2010).

While a salutogenic approach has been considered for studies of health promotion initiatives in schools, young people's engagement in community sport (looking at non-elite participants specifically) and engagement in physical activity by older people living in residential care homes(Thedin Jakobsson, 2012; Wootten et al., 2021), few studies specifically consider MS and the salutogenic framework. A narrative case study of a paralympic gold medalist utilised a salutogenic lens and concluded that health professionals should apply salutogenic approaches to better understand exercise behaviours for those people diagnosed with MS. A focus on the role and health benefits of physical activity, from the perspective of a person successfully navigating the symptoms of MS while also maintaining high levels of physical activity, takes the focus away from the absence of disease being the primary goal(Kean et al., 2018). An article by Hunter (2020) sees the value of Antonovsky's Sense of Coherence (SOC) model to provide guidance and empowerment for those diagnosed with MS. The article opines that a benefit of the SOC framework is that it is a measure to assess the capacity of people to understand what is happening to them, the extent to which they can manage the situation on their own or with the support of the community, and the ability to find meaning in the situation(Hunter, 2020). The concept of Antonovsky's sense of coherence scale is expanded on below, together with how it influences the research undertaken for this study.

Sense of coherence (SOC)

The health resources that are available to people were of interest to Antonovsky (1987) and he developed a specific framework to analyse these resources. The sense of coherence (SOC) model developed by Antonvosky had three components – comprehensibility, manageability, and meaningfulness. This SOC was reflected in a person's ability to understand what happens around them, to what extent they were able to manage the situation on their own or through significant others in their social network, and the ability to find meaning in the situation that they found themselves, to move in a direction of health promotion and to have the capacity to do so(Eriksson & Lindström, 2005).

If adaptive coping with life's stressors is the secret of a movement toward the healthy end of the health ease/dis-ease continuum, then primary attention must be paid to what Antonovsky (1993) calls "generalized resistance resources" (p. 725) and why such resources such as wealth, ego, strength, cultural stability, and social support promoted health. Antonovsky developed what he termed a Sense of Coherence (SOC) and the utilisation of these generalized resistance resources by a person is seen as leading to life experiences that promote the development of a robust SOC, or a way of seeing the world. In turn, this utilisation facilitates successful resilience to be able to cope with the many complex stressors that confront us during the course of life(Antonovsky, 1993).

The concept and advantage of a sense of coherence as defined by Antonovsky is in the cross-cultural and cross-situational character of the SOC construct. The SOC is a universally meaningful construct, one that cuts across gender, social class, region, and culture. A systematic review by Eriksson and Lindström (2005) found the SOC construct to be reliable, valid, feasible, and cross-culturally applicable. It does not refer to a specific type of coping strategy, but to factors that, in all cultures, are always the basis for successful coping strategies(Antonovsky, 1993; Eriksson & Lindström, 2005).

However, the review by Eriksson and Lindström (2005) does not recommend the use of the SOC questionnaire as an instrument for evaluation of a person's SOC. Instead, they suggest that the concept should be implemented as a systematic orientation and perspective in the actions of clinicians and professionals via a purposive change in the focus from problems and obstacles to the resourcing that is available to be utilised(Eriksson & Lindström, 2005). Therefore, instead of asking why those with MS stop being physically active, the focus is on why and how they participate in physical activities.

Influence on Research Design

The focus on how and the meaning those with MS ascribe to continuing to be physically activeis the reason salutogenesis and the concept of SOC is an important construct upon which to inform this study. With the symptoms of MS being different for each person, in both how and when symptoms present, their level of physical or cognitive disability, and ability to participate, it is appropriate for an investigation as to what and how the generalized resistance resources referred to above are utilised and relied upon by those people with MS who are physically active. Capturing the lived experience through the lens of salutogenesis will inform us as to what is required to support those people with MS who are struggling or finding it difficult to cope with the physical limitations of the diagnosis.

The current study uses the philosophical grounding of salutogenesis and Antonovsky's (1993) concept of sense of coherence as a guide to how the questions were formed and asked. This change in perspective led to the basis of the study being positive, curious, and forward-looking in its investigation. The practical aspects of this grounding and its influence are discussed in the following chapter.

CHAPTER FOUR - METHODOLOGY/RESEARCH DESIGN

This chapter describes the method of examination and analysis of the lived experiences of the participants within the conceptual framework traversed more fully in the previous chapter. The experience of multiple sclerosis is subjective and presents itself in different ways and at different moments for everyone. To make sense of how, why, and what facilitates physical activity for each person with MS, there is a requirement for an exploration of how it feels for that person, in addition to investigating a process or promoting a series of steps to follow. The use of qualitative phenomenological research approaches such as ethnography and narrative, are a way of people sharing their lived experience. This sharing of lived experience can in turn explain the meaning people with MS ascribe to being physically active.

The theoretical frameworks which guided this research are underpinned by social constructionist principles. Social constructionism embraces the view that what we know is shaped subjectively, that truth or meaning comes into existence out of engagement with the realities of our world, both social and natural. In this understanding of knowledge, different people will construct meaning in different ways even concerning the same MS diagnosis. Social constructionism shapes how we see and feel things(Crotty, 1998).

The use of this framework as the epistemological basis of this study enabled an appreciation of the lived experience of those diagnosed with MS, illustrates the unpredictable nature of their reality together with the various social and cultural factors that shape and influence it. How each person with MS views and utilises physical activity on a day-to-day basis, and the role it plays in their life, gives context and meaning when considering how to promote physical activity to those people with MS who are struggling to be active.

Interpretivism

To obtain a deep understanding of human lives within their social world, this research utilised narratives. A narratives exploration focuses on the stories and experiences of individuals, how they make sense of their experiences and why they do the things that they do(Richardson et al., 2019). Narrative methodology falls within the paradigm of interpretivism, which seeks to understand what it is to be human, what meanings people attach to the events in their lives, and the story that captures the essence of the experience(Grant & Giddings, 2002). Interpretivism formed the foundation for the research in this study because it encourages exploration of the multifaceted and complex individualism of social phenomenon, considers human behaviour to be fluid and responsive to situations and events, and recognises the varied nature of meaning within our reality.

Interpretivism assumes that there is no social reality independent of that which can be accessed and known, and that knowledge is socially constructed, fallible, and subjective (Smith & Sparkes, 2009). This position of ontological relativism and epistemological constructionism allows for an appreciation of each person's lived experience with MS, the unpredictability of their reality, together with the various social and cultural factors that shape and influence it(Richardson et al., 2019). The researcher is a part of this knowledge construction and has an active role which will be discussed in Chapter 5 of this thesis.

The interpretivist paradigm makes use of in-depth interviews to gain a deep and rich understanding of participant perceptions and experiences(Espernberger et al., 2021). Similarly, Sparkes (1996) considers that narrative inquiry is a useful tool for representing experiences and the rich dynamics of subjectivity. The sharing of a lived experience, informed by the theory, encourages a reader to reflect on their own life, so that the experience and facts may resonate, and they may then draw sense from the richness of the narrative experience for their use and benefit. What motivates each person to be physically active is complex and intensely personal and collecting and connecting these lived experiences is a move towards finding a new way to represent research in this area. The research then becomes interactive, relatable, and engaging for the reader by narratives that resonate, evoke empathy, and vulnerability(Sparkes, 1996).

Pringle (2001) summarises the essence of narrative research as describing the lives of individuals in a story-like manner to "engender an emotional response from the reader […] and provide an evocative analytical tool"(Pringle, 2001, p. 429). In relation to this study, this understanding of the role of physical activity, how it makes a person feel and what it represents to a person is crucial in designing exercise interventions that are relevant, meaningful and adaptable for those with MS as they navigate the course of their diagnosis(Richardson et al., 2019). Drawing upon narrative research, I explore the change and flux in motivations required by each person with MS as they navigate their diagnosis and, more importantly, the role physical activity plays in their life. The strength of utilizing the narrative story is in the way it can illuminate the complexities and diversity of people's lives and motivations, and used in this research, can help to identify physical activity interventions and strategies which fall outside the "one fits all" model. In their narrative position piece, Smith and Sparkes explain that "a narrative is taken to mean a complex genre that routinely contains a point and characters along with a plot connecting events that unfold sequentially over time and in space to provide an overarching explanation or consequence (Smith & Sparkes, 2009). It is this sequence that forms the narrative within this study.

Reflexive Thematic Analysis

Thematic analysis was used in this thesis to organise and describe the data collected and transcribed by identifying, analysing, interpreting, and reporting patterns or themes across the interviews, but with the flexibility to provide a rich and detailed account of the data collected. It is an analytical approach that reflects reality, can be used to "unpick or unravel" surface realities and is appropriate for use when working with participants whose views are not known(Braun & Clarke, 2006). A core strength of thematic analysis is that it can be used to highlight similarities and differences across the experiences of those with MS and allows for social interpretations of the data(Sparkes & Smith, 2013). Interpretations were enriched by insights from theory, so analysis was an iterative and evolving process.

However, to fully appreciate the complexities of the role physical activity plays in the life of those people diagnosed with MS, it was important for this research to be able to absorb, dwell in and ultimately explain the experience of that person, their views, and their relationship with physical activity. The only way to do justice to the story of a person's MS diagnosis was for the researcher to engage with the data organically. To this end, a more qualitative version of thematic analysis that advocates for a flexible approach to coding and theme development is required for this study. Accordingly, the current study used a reflexive form of thematic analysis.

Reflexive thematic analysis was a natural choice for me as the most appropriate method to analyse the data and to give a voice to the lived experience of people with diagnosis of MS and their relationship to physical activity. Reflexive thematic analysis utilises an inductive approach to coding and theme development and the subjectivity of the researcher is at its heart(Terry et al., 2017). Themes are those patterns of shared meaning across the dataset, and the process of analysis, by its very description, requires a reflexive researcher and their thoughtful engagement with the data and the analytic process(Braun & Clarke, 2019).

To that end, researcher subjectivity was a resource for the study, with the researcher being an active agent in the production of knowledge. This required the practice of "bending back upon the self" for the researcher to recognise the impact their experiences, emotions, self-awareness, and assumptions bring to the analysis(Corlett & Mavin, 2018, p. 8). Reflexive analysis is a creative process, a result of the researcher's engagement with the data, their analytical skills and experiences, and personal and conceptual standpoints. As a result, an awareness of where the researcher is positioned concerning power relations within the data collection process was required(Sparkes & Smith, 2013; Terry et al., 2017; Trainor & Bundon, 2020). The quality and rigor of analysis and the thematic analysis process itself will be covered more fully in Chapter 5 where researcher reflexivity and positionality are discussed

CHAPTER FIVE - METHODS

This study is guided by the salutogenic framework and the conceptual aspects of salutogenesis and the impact of the framework on the narrative methodology were discussed in the previous chapter. This chapter discusses the practical and philosophical aspects of the methodology used and the steps undertaken by the researcher to give rigour and validity to the lived experiences of the participants. Most crucially, the methodology utilised in this research places the researcher within the data collected(Terry et al., 2017), and therefore my positionality is an important factor upon which to be fully transparent during the process of analysis.

The analysis of the data collected began with an acknowledgement that because social interactions are at the heart of this research, the researcher herself was very much an active part of knowledge construction and the shaping of understandings(Richardson et al., 2022). That acknowledgment aside, it is the voice of those with MS that was the prime focus of this study and the practical elements of recruiting participants and collecting this rich data are described next. Thereafter the process of analysis is described, which is influenced by the aforesaid role of the researcher and the unique impact of her positionality on the research.

Data Collection

Sample

A purposive sample of physically active people with MS were sought for this research. Criteria for participants were those who had been undertaking physical activity on a regular and consistent basis since diagnosis. The level of physical activity for inclusion was based on participants achieving physical activity levels above a Metabolic Equivalent of a Task (MET) rating of 2.5. This MET rating is defined and assessed in the 1993 Compendium of Physical Activities and would include activities such as walking, playing croquet or golf, childcare activities, stationary biking and similar(Ainsworth et al., 1993). Additionally, as the primary research objective was to gain insight into the experiences of the ordinary person living with MS, any elite athletes were excluded from the study, as there is previous research that has explored the lived experience of physical activity of elite athletes living with MS(Fasczewski & Gill, 2017; Kean et al., 2018). By focusing on the experience of non-elite physically active people with MS, this research would be more relatable to the general population of people diagnosed with MS(Thedin Jakobsson, 2012). Likewise, those potential participants who were currently undertaking rehabilitation exercises as their predominant physical activity were also excluded from the sample. This is because rehabilitation directly influences a person's choice about participation in physical activity. Further, as an in-depth interview process was involved in this narrative study the participants were required to be able to communicate and be understood clearly by the researcher. Potential participants were screened via a 3-step telephone command test and all participants were cognisant and able to speak clearly to the researcher before arranging the in-depth interview.

Participant Recruitment

I approached the Multiple Sclerosis Society of New Zealand (MSNZ) with a request for an advertisement to be placed on the research section of their website. I also approached the Auckland Multiple Sclerosis Society and requested an introduction at the local support groups so I could speak with attendees, answer questions, and disseminate the advertisement. With the support of the Auckland MS community liaison, I attended support groups and was introduced to the groups and distributed flyers. Two participants were recruited through the support group meetings. The connections made at the support group meetings were invaluable in that they gave me, as an outsider to the MS support system, insight and confidence in my ability to connect with those with MS and build relationships and rapport with potential participants. The concept of my positionality as an outsider, both to an MS diagnosis and to having a medical or clinical background, will be discussed in the next section.

The advertisement on the MSNZ website attracted the most participants, with four participants emailing me with interest in the research and a further participant expressing interest after the analysis had been completed. I was unable to pursue the latter interview due to it being outside the time limit for the period of recruitment and requested that the MS Society remove the advertisement from the website in October 2023, which they confirmed. Additionally, two further participants were recruited through a snowballing sampling approach through word of mouth via university colleagues and contacts in the local community.

Ethical considerations

This research was approved by the Auckland University of Technology Ethics Committee (AUTEC) under approval number 22/101 (see Appendix A). Ethical guidelines further required that participants were informed about the purpose of the research and provided with an information sheet outlining the purpose (see Appendix B). Participants were requested via email to sign a form that stated that they consented to participate in the research, that participation was voluntary and that they understood the process and could withdraw at any time. Their anonymity was explained, and a copy of the signed form was returned to the researcher, with the original being retained by the participant (see Appendix C)

In all cases, the participant was contacted by telephone by the researcher before the interview to ensure that the participant was cognitively able to complete the interview. A short telephone conversation was undertaken which required the participant to be able to answer the phone and follow simple instructions. All participants were deemed competent based on this initial step to take part in the interview.

Interview design and process.

Reflexivity

A lot of time and space was taken to ensure that the interview questions and research were rigorous and that the role of the researcher in the data collection was given adequate consideration and acknowledged throughout the research journey. A major part of this preparation was in the area of researcher reflexivity, and ensuring this was practiced throughout the course of the research. Reflexivity represents more than just a researcher's social identity or positionality, it is about the active role of the researcher in the production of knowledge and the awareness of the complexity of that role as the research progresses(Trainor & Bundon, 2020). Reflexive practice involves acknowledging and thinking about how the researcher's theoretical perspective shapes both the data collection and the analysis process. For this to occur the researcher must be open to scrutiny, be aware of any bias or assumptions together with the distinct yet flexible role they have in how the participants will engage with the research and they must self-evaluate that position continually(Corlett & Mavin, 2018; Lees et al., 2022).

As a researcher, it was important for me to question the knowledge I had, my relationship with the research context, the participants and the data, and the value of the research itself. It was also important to recognise that researcher involvement was contextual, dynamic and fluid and would impact my interactions with participants throughout the data collection and analysis(Soedirgo & Glas, 2020). I did this in two ways; firstly, I undertook a reflexive interview with a senior academic and secondly, I engaged the use of an academic or critical friend to assist me in both recognising my positionality and feeling comfortable with how I formulated questions, approached the interviews and how I would be perceived and understood by participants.

Reflexive interview

A reflexive interview is a tool whereby a qualitative researcher is interviewed about their practices, their views, the way they will conduct the research and their knowledge, and as a result, the researcher becomes aware and sensitive to their significance to the research process. The researcher is deeply intertwined in the data that is generated, through their involvement in both data collection and interpretation; therefore, they must reflect on what they bring to the interview process. It is also useful during the process for the researcher to experience how it feels to be interviewed and to consider and be prepared for any ethical dilemmas that may occur, thereby minimising any negative impact on the participant(Bryman & Cassell, 2006).

Before any participants were recruited, a reflexive interview was conducted between a senior academic and the researcher. This interview was useful for evaluating and acknowledging what I brought to the research, any assumptions I had, and whether and how much I would disclose about myself to the participants to either make them feel safe or to encourage the sharing of experiences. I also reflected on how to deal with silences or upset, anticipation and redemption of negative trajectories and considered the questioning and phraseology I would use that would avoid encouraging a deficit way of thinking in the participant.

In the researcher interview, I experienced two levels of reflexivity. Firstly, I was encouraged and stimulated to think about the nature of my interview practices and their limitations, to consider my positionality and how safe participants may feel in sharing experiences about physical activity, particularly given that I am an active person, and to reflect generally upon the craft of my research. Secondly, during the interview, I became acutely aware of the significance of myself as a researcher to the outcome of the investigation, experienced a growing appreciation of the connectedness I would make with the participants and reflected on the assumptions I had about the nature and experiences of those participants. These aspects of reflexive practice, both concerning the collection of the data and the analysis, are discussed below.

Positionality (insider and outsider perspectives)

The foundation of active reflexivity is to accept the complexity, contingencies and humanity of our encounters with other people and these reflections need to be active and ongoing throughout the research process(Soedirgo & Glas, 2020). Initially, I considered myself to be an outsider in a health sense, in that I was not a clinician nor had I any experience with MS and considered myself an insider in a physical activity sense, such that I valued and appreciated the benefits of movement. I believe my value as an outsider is that the participant is deemed to be an expert in MS, familiar with the treatment modalities and would therefore feel empowered to speak about their own experiences, both negative and positive. I was "naïve" and curious about the participant's lived experiences and could actively seek clarification, while participants could feel open in speaking to me in detail about the way they navigated living with MS and being physically active(Hayfield & Huxley, 2015).

With respect to being an insider by being physically active, the question put to me to consider in the reflexive interview was how much of myself would I disclose and how safe would someone feel speaking to me who may be less active in a relative sense. Disclosure of my lack of knowledge of MS was something I had considered, and I was happy to be open about, but disclosure was not something I had considered when thinking about my levels of physical activity. The fact I was a long-distance runner and very physically active was not something that I chose to disclose to the participants. Reflecting on this, the suggestion that those participants may feel a disconnect with me on the basis that I was a postgraduate student in the study of sport and recreation, was in and of itself an assumption that the participant would feel diminished when speaking about their physical activity. In fact, several participants did question whether they were physically active enough to take part in the research. By framing the study to include all movement above 2.5 MET this opened up the levels of activity so broadly to allow participatory activities and it meant that woodworkers, mothers, swimmers, daily walkers, yoga participants, wheelers and endurance athletes felt comfortable sharing their activities for the research. The openness of the questioning to be around daily movement, rather than levels of physical activity, allowed participants to share their experiences of movement positively and to such an extent that I was never asked about my physical activity preferences or levels during the course of the research.

Academic or critical friend

An additional strategy to explore active reflexivity is to bring other individuals into the reflection process. One step was through the reflexive interview as discussed above but a further test of connectedness, or guide on how I would appear and be understood by participants, was to bring someone else into the reflexive process. Bringing a fellow student or colleague into the process to shed light on the dynamics of positionality that may not have been previously considered is one of the four strategies discussed by (Soedirgo & Glas, 2020) to assist researchers in being actively reflexive. The use of an academic or critical friend is also referred to in the self-study critical friend model (SSCF) outlined by (Smith & Bradbury, 2019) for use in education research and practice. The SSCF is used to promote collaboration between colleagues so that a person can be open to seeing themselves, as others see them. In the Foreword of Felten et al., (2013, p. xv as cited in Smith and Bradbury 2019) it is described as "befriend(ing) the hidden wholeness within us".

I met with a critical friend, a fellow Master's student in the Health Sciences faculty, to discuss my study, review the questions I had prepared and to test these and discuss how I would approach the interview. My critical friend pointed out several aspects of my positionality, which I had not previously considered. One was in the way I was asking the questions. My initial draft questions had been described as confronting and several changes were made to the interview guide as a result of the meeting. To begin with, my critical friend suggested I ask the questions more simply and to more accurately reflect the essence of what it was that I wanted to know. She suggested I explain exactly what it was I wanted to ask – "say it the way you would say it". This changed the dynamic of the questions markedly and, consequently, the entire way I was going to be perceived by the participants. Further, my critical friend pointed out that the way I appeared to be, fit and healthy, and how I felt about physical activity was part of my positionality and would likely impact research interactions. This was not something I had considered, and it played a role in my decision not to reveal that I was an ultra-distance runner to the participants and to positively accept the participants' view and level of what physical activity is. I would, however, use my age, enthusiasm for movement and curiosity about MS to connect and open discussions between myself and the participants about the role that physical activity played in their day. These meetings with my critical friend shed light on further aspects and nuances of positionality of which I had not been aware and were greatly beneficial to encouraging reflexivity in myself that I continued proactively throughout the research process.

Interview Questions

In line with a narrative format, a semi-structured interview was utilised to elicit rich experiences and to allow the voice of the participant to dominate. It was important to maintain some structure for the interview to elicit primarily positive experiences consistent with the salutogenic philosophy, but still allow the space for participants to take the interviewer along lines of inquiry that may not have been previously considered(Trainor & Bundon, 2020). Therefore, a semi-structured interview guide (See Appendix D) was developed by the researcher and refined with the help of a critical friend. Using salutogenesis as a guiding principle influenced the decisions around how the interview was structured and was important for this research. To elicit a thick description of life patterns throughout the course of an MS diagnosis and the role of physical activity in day-to-day living for the participants, the questions needed to be positively focussed and open. This positive openness was fundamental in gaining an understanding of the adherence-enhancing or health-promoting salutogenic strategies that participants used to continue moving and being physically active(Midtgaard et al., 2012; Mittelmark et al., 2022).

The study by Midtgaard et al. (2012) includes examples of open-ended questions as triggers to facilitate story telling from their participants and to measure the participant's sense of coherence (SOC). As this research was inductive in orientation the concept of SOC was instead used to support a salutogenic hue to the data collection, with the sample questions having a positive focus on resources available to be utilised by participants, rather than asking about the difficulties or obstacles that they faced(Eriksson & Lindström, 2005). The sample questions drafted together with my critical friend were similar to those utilised by Midtgaard et al. (2012) and the additional conceptual guidance of SOC on the framing of those questions solidified the focus for this study to elicit open and positive experiences about physical activity. The questioning during the interview allowed for a free-flowing sharing of experience, with further probing for more information or elaboration if required. Not all questions were asked if the subject of the question had already been traversed during the interview. The final sample questions are attached at Appendix E.

Transcription

Interviews were recorded and transcribed automatically via Microsoft Teams, or by the researcher using Microsoft Word for the interview in person. A review of the transcript was completed by the researcher as soon as practicable after the interview, on the following day in most instances. The review accounted for and edited out errors in transcription due to interruptions or muffled speech and accurately reflected the way participants structured their recollections, which often included humour. In all but one case, the video or voice recording was played alongside the editing of the transcript. The transcribed interviews were not presented back to the participants for confirmation of accuracy, but an offer was made to the participants if they wished to have copies of the interview and/ or the research outcomes made available to them. No participants have requested a copy of their transcript, but several have requested a copy of the research findings once completed.

Data Analysis

Familiarisation with data

Following guidelines recommended by Terry et al. (2017) the familiarisation of the data began with this initial review of the transcript and 'hands on' editing of the interview. Several sweeps of the data, voice and video recordings took place during the transcribing process, and this resulted in deep immersion and familiarity with the data. Transcribing the interview myself (as opposed to outsourcing) was time-consuming due to the limits of the immediate transcript from the Teams recordings, however, the re-living of the interview through both audio and video was an opportunity to become intimately involved and engaged with the data(Terry et al., 2017). I was able to pay close attention to interactions with the questions, pauses in response, physical gestures which gave emphasis or explanation to an experience (which I documented on the transcript) and could note both the dark humour together with the vulnerable moments that the participants shared. While it took a long time, and often required repeat viewing and listening, it was an opportunity to really dwell in the data, get to know and understand the participants and become fully immersed in what they were sharing(Terry et al., 2017).

Coding and themes

Identification of themes and a familiarisation of the core data set occurred very quickly, with interviews occurring in quick succession, a tidal wave of transcribing, listening and deep immersion in stories all occurring almost contemporaneously, meaning that certain elements of the participants' lived experiences quite quickly became strongly evident across the dataset. Direct comparisons and reflections could be made intuitively and an immersion within the experiences in a short period was hectic but fruitful in understanding MS from many varied viewpoints. It also meant being inundated with experiences whilst remaining relatively naïve about MS. This meant that potential themes arose inductively, by asking questions of the data and recalling comments and statements that occurred across several participants as new transcripts were edited. Dominant themes started to be identified quite quickly and these themes are discussed in the next chapter.

Nvivo software (version 20), was used to store, manage, and code data. While Nvivo does have automated queries that identify themes, and produce reports and word frequency tables, the software was used in this instance as a useful way of storing, highlighting and grouping parts of transcripts. Coding was completed manually, transcript by transcript, and then the codes were grouped into similar ideas or themes, in a similar way as using highlighting or labels to group similar content together in one colour or box.

Once all the transcripts were uploaded, a deeper analysis involved sifting through transcripts back and forth for any further emerging themes. Prolonged data immersion, transcription and uploading to Nvivo over a period of a month, with new data being generated every few days through further interviews, meant analysis was a fluid, active and generative process in line with that described by Braun and Clarke (2019). To this end, supervisors were involved throughout the interview, transcription and analysis period, with constant revision and discussion of the data occurring regularly. In-depth discussion took place once the transcripts had been coded and as smaller sub-themes began to mould together and emerge into larger themes across the dataset. We discussed at length how to refine focus by considering and keeping within the scope of the research question. While the questions had been influenced by Antonovsky's SOC I was also conscious that I did not want to inadvertently become deductive in my analysis. This meeting with my supervisors was definitive in helping me identify the themes directly from the participant interviews I had before me, with some themes emerging very strongly. These themes and the voices of the participants are described further in Chapter 6.

CHAPTER SIX - RESULTS

Participants

A total of eight participants were interviewed, six female and two males, with seven of those people diagnosed with relapsing-remitting MS and one diagnosed with progressive MS. A variety and range of MS diagnoses, symptoms, stages, and physical abilities were reflected across the participant group with one being a wheelchair user and one relying regularly on walking aids. Seven of the eight interviews took place by video call (Microsoft Teams), and one took place in the researcher's home. Six interviews were recorded on video, over the period of one month, one digitally recorded, and one video call was prevented from being recorded by the participant's business internet security, but a direct transcript was made available and edited immediately by the researcher. In total there were over 8 hours of participant interviews with an average interview length of one hour.

Analysis

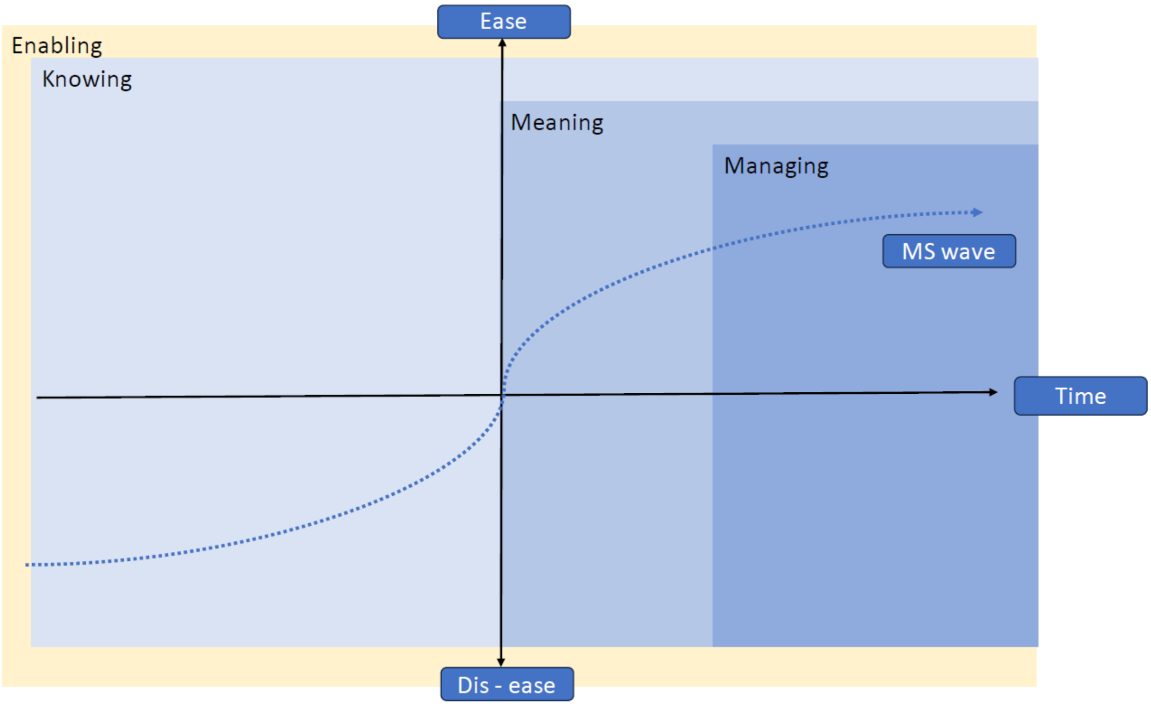
The following sections summarise the results of the analysis of the participant interviews. Most participants had similar experiences over the course of their condition, even though physically each diagnosis and stage of life was quite different, and themes were easily identified across the dataset as the stories of participants were collected. Four major themes were identified: Knowing, Meaning, Managing and Enabling. These themes represent the journey of the participants through diagnosis and learning to either adapt or manage being physically active around the varying symptoms of MS.

The themes are represented in Figure 1. below. The figure shows the unpredictability of MS (the MS wave) moving on the health continuum from dis-ease towards ease, over time, as meaning and managing take hold and participants put into place the strategies that they learn to assist them to engage in and maintain physical activity. It is analogous to the sense of coherence framework developed by Antonovsky (1987) which reflected a person’s ability to utilise resources to understand and find meaning in the situation they find themselves in, and thereby move in a direction of the health, or ease, end of the continuum.

Within each of these larger four themes, sub-themes illustrate the different utility for participants, depending on their lived experience, their MS diagnosis and how far they are through the course of the disease. While each participant’s voice is unique, each circumstance different, and the views shared intensely personal, when considered together they illustrate MS and its vagaries, its unpredictable progression and how this impacts how those with MS live with, manage, and experience physical activity.

Figure 1

Themes relating to Management of MS



Note: Each theme is represented by a block with the movement of the MS Wave indicating a person's journey over time towards Ease as they utilise each resource or theme.

Theme One: Knowing

Ability to assess, analyse, obtain knowledge, understand self and the situation

Knowledge of themselves, of the disease and its course was a dominant theme across all participants and is the core factor or golden thread that is present in each participant's experience in continuing to engage with and participate in physical activity. It involves the research and assessment that a person with MS does about their condition and is most prevalent in the early stages of diagnosis. However, it also relates to the skill to assess, analyse themselves and ascertain knowledge throughout the course of MS, and gives them confidence to advocate for themselves where necessary.

Self-diagnosis - I knew I had MS

Across all interviews, the journey to diagnosis was remarkably similar for each participant and had a direct impact on their motivation to continue to move and self-manage the symptoms that arose during the course of MS. All participants reported that getting a diagnosis of MS is a long, arduous process and symptoms are often present, but undiagnosed, for a long time. Participants recounted being either previously misdiagnosed or have known that the symptoms they were experiencing were MS but not advocating for themselves or, when they did, their view being minimised. Furthermore, some reported ignoring symptoms or justifying them as being transient and temporary. Once diagnosed, participants would express that they had been relieved to finally have an answer and that their symptoms had been validated.

> Well, first I went to A&E and they gaslit me and they're like, oh, we really recommend people don't Google like, it's not gonna be (MS), it could be a pinched nerve. And I was like, sure. OK, you do your thing and I know, so, whatever. Adelaide, age 29.

> I think I've probably had MS for much longer, so the first time I went to my doctor with symptoms of loss of sensation and pins and needles in my limbs was when I was 29 […] I was tested for stroke on a couple of occasions, but once like because I collapsed or whatever, but once they found I didn't have that, they just sent me home and said come back if you have any other problems. So there's kind of things that have gone on, you know that make me think that it's been a longer term issue. Kathy, age 61.

Self-advocacy - being “bloody-minded”

Participants often described themselves as “bloody-minded” or “determined” and all are self-analytical and wary of the medical system. Navigating the medical system and being diagnosed with MS has required participants to acquire in-depth knowledge about MS and its treatments, and participants use that knowledge to self-advocate wherever necessary. The self-advocacy continues for many participants as part of ongoing symptom management and has two different uses: the first is medical self-advocacy and the approach participants take in standing up for themselves and the treatments they choose for managing symptoms; the second is physical self-advocacy (or being “bloody-minded”) around the assumptions they experience from others as being a person diagnosed with MS.

As to the advocacy in the health or medical setting, several participants report adverse, uncomfortable or unwanted side effects from the pharmacological treatment of MS. As a result, several participants choose not to take any medication for some time or at all, often against medical advice.

> I started taking this medication (Fingolimod/Gilenya). Obviously, the side effects are quite different and it's a suppressant, so, and I was finding it was actually making me feel really bad and far worse. So, I took myself off it as much to my neurologist’s dismay. He advised against it and I said no, I don't want to be on this, it's not making me feel good and I also believe that with exercise and good nutrition that I can actually go you know go it alone. And not have any drugs. Denise, age 49.

If the medication was tolerated, participants still utilised physical activity as a form of backup treatment, with the concern that, potentially, pharmacological treatment would only work for a certain period of time.

> I'm JCV (John Cunningham Virus) negative so I can stay on it for a while. So I don't, the big thing for me is like what happens? Where to next? because it's not an infinite drug. Sharon, age 51.

The second element of self-advocacy for the participants is control over their physical capability and rebellion against the assumptions that are made about the limits participants have as a result of being diagnosed with MS. Regular physical activity and movement are considered by participants as a key part of their ability to deal with MS, physically and mentally, and the activities the participants choose to partake in are endless and varied. Participants described being determined to continue to be physically active in whatever ways they can, even if it is outside of their regular physical prescription.

> You know, they go to the gym and there's people that run and stuff like that and I think ohh good on you. You go do an extra 10 for me, I say. Because I'm doing my thing [...] and it's enough for me, yeah. Marion, age 60 (woodworker).

> So, what I've had to adjust in my mindset, especially for physical activity, and I've been able to, probably only do it this year, is not worry about where I come in the place. Not worry about time [...] one thing I will never do, no matter what, is ever quit" Angus, age 51 (Ocean swimmer, walking, hiking).

Self-confidence – knowing limits.

The participants educated themselves about MS, and its impact on their physical ability, energy levels, and social capacity. All participants used this knowledge to give them the confidence to extend themselves where needed or to take time out if required. This deep knowledge of how MS impacts their overall well-being is a rich resource utilised by participants to help them navigate daily life with an element of certainty.

> So probably a week after I had the episode, I jumped onto my mountain bike on the grass outside with my son and I fell off as soon as I got on. I fell over straight away. The balance wasn't there, and so it took me a long time to get the confidence just to ride, go around the block, you know, and then just do a check as I was just if I'd moved my head away, it was like I said earlier, just end up drifting and that's a lot better now, but I've still gotta concentrate on that side, so I still intended to go up with my mates. Ian, age 46.

> I can't deal with too many people or too much interaction with people. So I tried working in the Hospice, not in the hospice shop another op shop and it was just too much having to deal with customers and stuff all the time. So, yeah, it's that does cause me fatigue, but it also causes me anxiety. Whereas I can actually go out and do something physical for quite a long time. And because I don't have to use my brain or think about it or I didn't have to interact. That's actually beneficial to me, rather than, it has more of the positives are greater than the negatives. Kathy, age 61.

Knowledge gives these participants a sense of control and it encompasses not only knowing the symptoms they experienced prior to diagnosis might have been MS, but also involves knowing the ins and outs of the the disease course of MS and how it might affect them on a day to day basis.

Theme Two: Meaning

The wind beneath my wings

Once participants have gained knowledge and have assessed their situation, the motivation to manage being physically active with MS is multifaceted. The ability to manage the course of one's diagnosis through maintaining a level of physical activity gives those people with MS a sense of purpose and a feeling of accomplishment. Subthemes behind the meaning or "why" the participants sustain a level of physical activity are twofold, first and foremost the participants refer to "myself" and the internal reasons to be active such as feeling better, feeling accomplished, feeling lucky and having a determination to not be defined by MS; secondly, participants want to be more active for others and because of the external social support that they receive as a byproduct of taking part in everyday activities.

Myself

The participants often referred to themselves as being the reason why they continued to be physically active.   Many participants described how they wanted to have a normal life and that being physically active helps maintain a sense of control over themselves and their future. Participants reported feeling better as a result of being physically active and being proud of what they had accomplished, even if it was a seemingly small achievement, like being active around the house, caring for children, or going to the supermarket without having to take a rest.

> Just it makes me feel like accomplished and that I can still do that kind of physical activity, whatever it may be, whether it be going to yoga or to physio or just kind of like I can want to if I want to get out and go to say, go to a shopping mall to get something I can physically go by myself and like whizz around the shopping mall kind of thing and then get back in and then that type of thing so. You know, yeah, there's it's really important for me, really, really important to keep as much as I can physically active. Margaret, age 61.
>
> You know what? I feel really, I feel at peace with myself. Because I can do these things by myself, right now, you know. And I mean, you know, as you know, I've seen many people that can't get out of their own way. Sometimes I'm like that. Sometimes I can't get out of my own way too. But the awareness I have around and that's, how do you put it, a spiritual awareness as well as you know, cause I've been down that track. I'm on the other side sort of thing. Not that you ever lose it, but just having the awareness of getting myself to do these things, I'm proud of myself. Marion, age 60s.

Participants described their reason for continuing to be physically active from the perspective of what being active could achieve for them and how it helped them participate in and enjoy a normal life and activities, on their terms. Almost all participants reflected on how lucky they felt to be able to cope, and to have had the time and space to adjust to their diagnosis, obtain knowledge and learn new skills.

> I just, you know I've been really fortunate to have a really good life for 50 years and be all around, you know, done a lot of traveling around the world, done a lot of sport. I haven't. I didn't hit me at 20, this MS. So I've been able to do so many things. So I'm OK with that. But I'm also, not OK that I'm just gonna stop. I'll keep going, but I'll … It's only in the last little while I've just adjusted my mindset so to you know, it's still doing 1 1/2 K or 2K swim is fine and it doesn't matter what time or whatever or going for a walk. And I've and I've started to use aids as well, which I was dog determined I never would. Angus, age 51.
>
> I've really noticed a big you know a slight change and I'm getting, especially in my extremities, I'm getting a lot of loss of feeling and numbness. Uhm, but you sort of learn to live with it and you get used to it. But some days I feel like I've got lead in my legs, feel like I've got concrete shoes on. Uhm but but compared to so many people, I am so fortunate and lucky. Denise, age 49.

Others

Less often, participants referred to other people as the reason that they were physically active. Participants described a need for their partners and children to see that they are taking part in everyday life, a desire to lead others by example and to participate in work and do things to the very best of their ability. Whilst this sub-theme formed part of the participants' "why", it was in addition to the self-motivation described above, it was external and grew from another person needing help, companionship, or support from the participant.

> You know, I think I'm gonna cry, but it's my children that motivate me, you know. It's them that motivate me. And it's also my job. You know, I work with really, really good people, you know, and and the and the job itself motivates me because I still want to be kind of um I still want to be able to be like carry out a job you know, and to do it to the best of my ability, you know, and also, you know I'm also another thing that motivates me, Deb is I'm gonna become a grandmother in March. Margaret, age 61.
>
> My daughter was into, actually what happened was my daughter had issues. Umm. Like mental health issues. So I thought, right? She loves art and craft. If I can get her into the shed, to doing this stuff, you know, maybe it'll help. So that's when I got into it. But I ended up in there, doing it and she and then she, I think she got annoyed because I was always out there doing it so but she eventually got on track so it was good, yeah. Marian, age 60s.

The theme of meaning comprises the participants' purpose for continuing to be physically active. Overwhelmingly, the participants here explained that the "why" was themselves, they were active specifically for how movement made them feel, but also there were instances where being supportive, being with or inspiring others featured as a reason to continue to be physically active.

Theme Three: Managing – Riding the wave.

Holding MS at bay

Keeping the symptoms of MS manageable and being able to cope with fatigue, remission and relapse is a day-to-day occurrence for those people with MS. There are two aspects to holding MS at bay reported by participants; the first is being willing and able to adapt, for example, listening to body signals and altering the course of the day to avoid fatigue is a common strategy, as is sleeping more and improving diet to maximise energy. Other adaptations include the use of walking aids, electric bikes or wheelchairs to continue to maintain a level of physical activity.

Secondly, participants express that they do not want to be defined by the diagnosis of MS. Participants describe a need to have a normal life and voice fears of "what could be" if the symptoms of MS are not managed. Participants are aware of and know that physically and mentally life is more manageable when they are active, and this is a driving factor for many participants to keep MS at bay.

Being willing and able to adapt.

Participants report that a vital way to manage continued physical activity is to be willing and able to adapt. Knowing what their alternate options are and having them available when required is key to participants continuing to be physically active. Some participants utilise mobility equipment, such as walking poles, while others have alternative plans to complete activities if they are unable to physically take part. Participants explain that they are prepared to compromise on an outcome or have an alternative means to partake in certain activities, for example, an alternate route if stairs cannot be managed.

> So it's all those things that I've changed my mindset on, so I've had to. I saw those things in the past as disablers, making you more disabled. But now I've had to change my mindset to see them as enablers to help me enable me to keep going with what I'm doing. Angus, age 51.
>
> And if you don't, then you have to adapt, which I was prepared to do. I was prepared to ride an ebike if that was what was, you know, ultimately what I had to do? Kathy, age 61.

Another form of adaptation reported by the participants is being vigilant to ensure that their fatigue is managed, with energy resources being used appropriately. Participants report that they go to bed early regularly to ensure they stay on top of symptoms and take adequate rest when the first signs of MS symptoms return. Participants describe how they need to consider and constantly manage every part of life; sleep, diet and levels of physical activity are always finely balanced.

> So what I what I had was a slight tingling in my hand every now and again I would get really tired I'd get this little wee tingle to remind myself almost like you're overdoing it you know and they just came back a little bit and then eventually it just it just wore off and you know, to this day, I don't have it, but I used to get a tingling and then I used to, this is always my sanity check. I do here (shakes hand) and if this hand keeps wobbling it'll be like OK, we need to … but I don't have that problem now, you know. Ian, age 46

> I'm quite disciplined about being in bed by 9 o'clock take my devices off, you know, like my phone. I turn off at nine, try to do, like, quite good sleep hygiene to try and yeah, stay on top of it (MS). So I’m quite good about that. Sharon, age 51.

MS does not define me

Participants describe that the need for them to be “normal” (or not wanting to be defined by MS) is an important part of continuing to be physically active. Participants also explained that they have a fear of what could happen if they do not continue to be physically active and, as a result, lose the version of normality that they currently have. The perception of “normal” for each participant was relative, for some, it was to be a parent, to be able to manage or cope with children or grandchildren, and for others, it was holding down a job or taking part in physical activities with others. Some participants recounted how they look forward and focus on what they can do, without any consideration of what they cannot do.

> I've been very, I didn't want (MS) to define me, you know? Like I just. Yeah. So maybe I could be a little bit easier on myself, but I also don't want it to be who I am. And I wanna do as much as I can. Sharon, age 51.

> I don't, I don't think about, if I can't do it. Sometimes I do, sometimes I think ohh better start looking for somewhere where it's really flat, but that lasts for about 5 minutes and then it's like Nah, just carry on. You'll be right. Marion, age 60s.

However, the participants also reflect on the effort they make to be “normal”, and take part in everyday activities, and describe the concentration, planning and preparation it takes to do the simple things. The efforts recounted by participants to do everyday activities are often beyond anything evident from outward appearances, with several participants recalling in detail the extra efforts they make to take part in the activities they enjoy.

> And I'll tell you what, like for yourself and I have to, I have to concentrate so hard just to walk. I'll make it look easy, but I'm concentrating every single step where I never had to concentrate how to walk. You know, people just take it for granted, you know, just put one foot in front of the other. But I have to concentrate because my nerves aren't going, signals aren't going properly. I make it look like I walk fine, but every single step I'm like, you know, I have to now when I cross the road, I'm like there's a car 100 metres away. I can't run, so I've gotta now think Ohh, I'm just gonna have to wait here until that car goes by until it's totally clear. Cause if I stuff the crossing up, there's no way out. Angus, age 51.

> And I'm as I say, it's just I've gotta pay attention. You know, I I nearly ran my mate off the road the other day because just what I said, if I, you know, reached down, picked the water bottle up, slightly veered to the left, and there was a pothole in front and I ended up seeing it really late […] it's just little things like that where I've got to think to myself, OK, just reach down and get the drink bottle. Don't put your head down. Ian, age 46.

Participants who have relatives with MS have a unique position as far as seeing the outcome of MS for those that they love. Several participants recall seeing older relatives experience MS and the recollections are reflective and thoughtful, but the participant's view of the MS journey for those loved ones is not positive. Several participants also mentioned encountering other people diagnosed with MS while in treatment or while attending support groups. Seeing how MS progressed in others was an incentive for participants to do all they could to prevent any decline in activity. Participants expressed fears about what might happen to them if they stopped being physically active and their physical disability progressed. Some expressed concern that if they did not "use it" they would "lose it", particularly those who were experiencing difficulties with mobility, while others saw the positive benefits of physical activity and how it made them feel good, and therefore made them a better, happier person.

> I just see this like, sick, bitter person in pain, who's kind of losing her marbles. And to me, that was all MS. And I just was like, whatever I need to do to not be that. Adelaide, age 29.
>
> I did the that North Island ride and I felt like I just want to keep riding because I'm scared because I know if I stop, I'm actually not gonna feel as good just going back to doing what I normally do and I was actually quite scared about stopping. Kathy, age 61
>
> Oh yeah, my logo is "Use it or lose it" kind of thing and even though the MS you know kind of rumbles along as I call it, and kind of like, you know my MS definitely does, it progresses, and that you still got to do what you can, kind of thing and for example, I used to go water walking at Takapuna pools, and that was just up until recently cause they've got like a hoist, a chair hoist, that dips me into the water and COVID kind of, it just got too hard. It got too hard and I was doing it for, like years and years, but kind of with COVID the pool shut down for about, God, I don't know, it was probably a long time. And then I kind of, yeah, it just got too hard for me and but so therefore … let's try something else, you know. Margaret, age 61

The theme of managing or keeping MS at bay involved two aspects, the first encompassed the physical management of the condition, learning their limitations and knowing when to push and when to slow down. It involved tirelessly staying on top of symptoms, reading signs their body was telling them, and when necessary, making an adaptation to compensate. The second part of keeping MS at bay concerns being their version of "normal" by not letting the symptoms of MS constrain or limit, but instead doing whatever they could to continue feeling good and being happy.

Theme Four: Enabling

Having the capacity and support to keep going

This theme relates to the support and facilitation that is available to participants as and when they need it to cope with stressors. The enabling theme encompasses the support and understanding from others, but it is not support that is interfering, taking over or being protective. Sub-themes relate to support from others with MS, via support networks and from family, friends and others who were not part of the MS network.

Support from those with MS

While participants' initial experience with medical and clinical evaluation surrounding diagnosis was often stressful, participants did value the input and advice of others who had also been diagnosed with MS. To this end, support groups, both online and in person, are valuable sources of advice, information, and support. Online forums, via Facebook and the MS Society with their links to international MS groups and courses, are utilised by several of the participants. Being an advocate and sharing information with others is often reported as an important aspect of these participants' experiences with the MS Society and online forums. Participants were often reticent in joining or attending support groups as their initial impressions were that a support group may have a negative impact by allowing members to 'wallow' in having MS. Participants reflect that, on the contrary, when they did take part that a large part of the benefit of a support group was being with those who understand what it is like to live with MS and that, because of partaking in these groups, they no longer felt so alone.

> But eventually curiosity got to me. And I joined a couple of Facebook groups and actually it's really helpful and it's a really good community of people, with like a huge mix of primary and secondary and relapsing remitting and ages and stages and capabilities and disabilities. And it's just really helpful to not, it's such a cliche, but to like not feel alone. And I think so much of my journey with MS has been feeling misunderstood, starting with like the almost 10 years of people just saying I'm lazy. And just having people. I'm trying to describe like obscure symptoms or like something I feel, in is this relatable? and everyone on the page has MS and they're like, "yes, I know exactly what that is, try this, try that" and I actually did find that really validating and helpful. Adelaide, age 29.
>
> I'm and I'm not and I'm no longer ah, you know, I'm no longer ashamed, you know, number of times I went to the toilet and cried, you know or I sat down, I went down to, we've got a field across the road from my school where I've sat down there when I first was diagnosed I thought my world was gonna end. You know, it's, I just, you just can't explain it unless, and the most people, I think you if you talk to about MS have been through that. And some of them, unfortunately have got progressive MS and they're amazing people because they're so positive. Angus, age 51

Support from others

Participants take part in regular exercise group activities such as cycling and swimming and enjoy the support from friends and family. They report that support from taking part in these activities and the social aspect of these kinds of groups are really important.   The participants have confidence and do not set limits for themselves, nor do they see any impairment in their abilities.

However, several participants commented that if they plan to do a particularly challenging activity, then they may need help breaking down the steps required to achieve that objective.

> I just do them at home on my own. I have enough confidence for me to do it. I do have my older sister, who's, she can, she's helpful with some. I find it hard, with the mechanics of things. I know what I want to happen, how it needs to work, but it's the mechanics. I can't get it out of here (indicates head) and on into my hands. So she helps me a lot. She helps me a lot. So. But yeah, I mean my whole family. I've got five siblings. So, you know, like everybody has an opinion, so you know, you’re not far away from somebody saying, Ohh, why don't you do that? Marion, age 60s.
>
> So yeah, that's that's probably where I am today. I still did like a mountain bike race last year. I did 25K race around Lake Rotoiti run down here recently, so I'm still really active physically per se, and it hasn't impaired me. Doesn't really impaired me too much now, which I look on, I coach my sons under 8 rugby team and all that. So I stay quite engaged socially, you know, play masters football, don’t know why I started playing football again. So I was like ohh and what had been everything to the MS? They just asked. And I was like, hey, I'll be there. Ian, age 46.

Several participants commented that finding the avenues to continue to exercise was hard. Those participants who were involved with, and highly active in, sports such as cycling, football and swimming reported how they continued with groups or squads that they were already affiliated with. Participants who wanted to extend their abilities or goals reported that they required specialist support or advice on how to scaffold activities to achieve these goals and that attendance at MS Society support group meetings was often a valuable way to source recommendations for contact names and numbers of health professionals that could assist them further.

> It's just, you know, you worrying about something that potentially isn't a thing. But I don't know because I don't know who to ask about that, you know, like. Most of the MS stuff and like the magazine and the MS society and that help is for the people that are quite incapacitated. You know, there isn't much around really, you know about people that are active. Sharon, age 51.
>
> “I told my neurologist that I had been planning to ride the length of New Zealand before I was diagnosed, the Tour Aotearoa. And um, she just went well, just do it. And to be honest, that wasn't helpful, because I couldn't see a way forward to just doing it, so when I went to the newly diagnosed meeting.I heard about this neurophysiologist, that was on the North Shore, so I instantly booked in with her because, that was that, and she was my lifesaver really” Kathy, age 61

Support and encouragement of others, and from those with MS through support groups, is crucially important to those with MS. However, the support does not constrain or ‘coddle’, it enables and participants know it is there and available to call on when needed.

Summary

This chapter has analysed the interview data and presented four themes which encapsulate the experiences of the participants as they journey through their MS diagnosis. The themes of knowing, meaning, managing, and enabling represent different parts of the journey, with each layer a distinct step for those with MS as they come to terms with their diagnosis and learn to manage or adapt to the new challenges that arise.

Notwithstanding the variability of their diagnosis, the accounts of each participant represented that they were proud of how physically active they were and what they could achieve, that they effectively managed any physical or cognitive flux to maintain a level of physical activity through self-knowledge and support, and in doing so, each participant felt a sense of control over their future health outcomes. The next chapter examines the significance of these results, gaining insight from the micro level of the participants' experiences and meaning behind being physically active and analysing how these experiences can give us a broader understanding of how health and physical activity narratives interact for those people with MS. Similarly, the impact of the Salutogenic model of health and Sense of Coherence will be discussed, and how those people with MS who continue to be physically active gain control over their health outcomes in a positive manner, despite the unpredictable course of their dis-ease.

CHAPTER SEVEN – DISCUSSION

Current socially constructed physical activity narratives, which are evidence based and endorsed by the governmental health agencies, involve an exercise as medicine narrative. That is, physical activity recommendations come with specifically prescribed minimum requirements for time and intensity, with the inference that if these targets are reached, then we will 'be healthy'. This physical activity narrative does not consider any subjective or sociological nuance, or indeed, the health status of the individual to whom it is directed, nor any intrinsic value there might be in being physically active. As such it becomes a constraint rather than a freedom. Similarly, health narratives surrounding physical activity divide the population into non-disabled or disabled, with suggested modifications relating to physical limitations. However, this distinction may be irrelevant for those who experience the episodic nature of a diagnosis such as MS. The insight and personal stories shared by the participants in the previous chapter intersect with both these narratives, and their experiences with physical activity challenge those notions.

The themes of knowing, meaning, managing, and enabling, and the manner in which the themes layer and concertina so as to give these participants a perception of control and an understanding of themselves and MS, can inform how clinicians can better enable those with MS to partake in and adhere to being physically active within these narratives. Furthermore, the way these participants navigated physical activity through their diagnosis represents a Salutogenic model of health, and I consider in this chapter whether the promotion of a patient-led or self-guided activity programme, tailored specifically for those with MS, may be a significant step toward increasing confidence in ability, reducing sedentary behaviour, encouraging physical activity, and therefore achieving better overall health outcomes for those who are diagnosed with MS.

Physical Activity Narrative

Participation in physical activity is important to maintain long term health and wellbeing and to prevent secondary complications that may result from a sedentary lifestyle. The dominant narrative, repeated to us through all forms of media, and through our health practitioners, is that we must exercise a certain amount daily, and the more vigorously we exercise, the less time it will take. The over-arching sense is that physical activity is a medicine, it is a burden, but it is necessary and, if we find the right activity, it could even become enjoyable. There is not context or consideration of the need, desires, and capabilities (whether time or ability) of the people to whom the prescription is targeted and no refinement or nuance to allow for anything less than the prescribed amount. The medicalisation of exercise in this way, is crowding out the many other positive attributes of physical activity(Adamson et al., 2017).

This section will discuss how every participant was passionate, engaged, and positive about being physically active, rather than feeling like exercise was a burden or a chore. As a result, these participants managed to maintain a level of activity that was unstructured, mentally, and physically uplifting, and suited their lifestyle. It was their choice as to what activity they participated in, and they balanced the symptoms of MS with family and work commitments to take an active part in whatever it was they chose to do. All participants saw the benefit of physical activity, found it fulfilling and empowering, and did it on their terms, without the need for prescription.

The medicalisation of Physical Activity

As outlined in Chapter Two, it is recommended that there is a need to partake in regular exercise a certain amount to for our general health and wellbeing. This requirement applies particularly to those diagnosed with MS, whose sedentary behaviour is the lowest of all those who have a chronic illness, and for whom exercise is crucial for long-term health and overall symptom management(Kinnett-Hopkins et al., 2017; Motl et al., 2005). As a result, there are Governmental and MS-specific guidelines for levels of physical activity, with MS Society websites promoting the benefits of physical activity, suggesting available options, and providing support through Health Professionals should it be required.

However, the guidance of both the Government and the MS Society presupposes the medical narrative that exercise will fix or improve us. Likewise, the lifestyle physical activity proposed for those people with MS by Kalb et al. (2020) is described in terms of a dosage, a daily accumulation of 30 minutes a day. Despite this being a small amount of exercise in daily terms, it takes the form of a prescription to be taken regularly with the additional pressure or requirement that it be adhered to, with the resultant guilt or disappointment if the period of physical activity is not completed. Given that this is a prescription to be followed, compounded with the efforts of those with MS to manage and navigate the uncertainty of their symptoms, it is no wonder those with MS find it difficult to be physically active over the long term and that there has been little change in physical activity levels over the last decade(Kinnett-Hopkins et al., 2017).

Prescribing daily amounts of physical activity means that movement can be perceived as disciplinary, potentially stripping it of the positive intrinsic values of pure enjoyment and self-care(Adamson et al., 2017). However, there was no mention by the participants in the present study of physical activity having a disciplinary focus. On the contrary, participants here speak positively about the reasons why they are physically active, in that it improves their mindset and ability to cope with everyday activities. Most discussions in this cohort are around the enjoyment they get from participating in physical activities, the social aspect, and the benefit it has to their quality of life in the long term. This is consistent with studies that have observed that people will participate in physical activity for longer if it self-paced and enjoyable(Lind et al., 2009; Williams et al., 2012).

There is, however, reference by the participants in the present study to a fear of the future course of MS when they speak of the desire to “hold it (MS) at bay” and “use it or lose it”. As noted by Adamson et al.(2017), this is a common motivation for individuals with MS as they assume an active role in treating their MS to prevent or remove symptoms or to avoid disability. While participants in this study do have a fear of the future, it is not a fear of the onset of disability as a result of being inactive; it is more a fear of the encroachment of a negative mindset. The motivation or “why” behind being physically active for these participants is about being capable and content, and as Denise explains, to not “live the disease (MS)”. Similarly, Adelaide refers to her relative as “a sick, bitter person in pain, who’s kind of losing her marbles. And to me, that was all MS”, while Margaret refers to her MS and how it “rumbles along” but that she just keeps doing what she can. Others refer to not being defined by MS and not submitting to negative assumptions, and this is reflected in their willingness to adapt to the physical and neurological fluctuations of MS and to continue being active no matter what.

To that end, the participants in this study use an array of resources, which includes physical activity, to navigate long-term overall health. Physical activity is not the panacea to try to cure MS or manage symptoms. Furthermore, physical activity has not been medicalised by these participants and there is no reference to any “dosage” or time requirements. The participants have gained knowledge over the duration of their diagnosis, of the condition and of themselves. With this knowledge they find unique ways to continue with physical activity for social benefit, to increase their self-confidence and, generally, participants say they just ‘feel better’ when they are physically active. Interestingly, the importance of social connection and taking part in meaningful activity was also found to be a factor in long-term engagement in physical activity for stroke survivors in the systematic analysis by Espernberger et al. (2021). Personal empowerment as a meaningful byproduct of being physically active is a factor in all the participants in this study wanting to continue to engage in physical activity.

Overall, the participants in the present study know and accept where their health is on the health ease/dis-ease continuum, use physical activity to feel good and utilise many strategies (for example medication, the use of “enablers” such as a Dictus Band, sleep hygiene, diet, and meditation) to overcome any change in symptoms, and to manage a positive trajectory of their MS diagnosis. For the participants of this study, it is evident that their attitude to physical activity was all-encompassing, positive and enjoyable; they did not refer to exercise or physical activity as something to dread(Adamson et al., 2022). The participants here are finding ways to be active, and the narrative of physical activity as a form of medicine, and its strict prescription may be constraining the wider benefits of physical activity. Prescribing activity makes exercise both negative and disciplinary, requiring constant vigilance and which thereby reduces physical activity accessibility and options for people with MS. Widening the scope of physical activity, emphasising the empowering and intrinsic value of movement, and the social motivations of being involved, may assist in promoting the general health and wellbeing imperative of physical activity and increase uptake and adherence.

Health Narrative

Sitting alongside physical activity for those with MS is the health narrative of whether they feel able bodied or disabled because of their diagnosis. The function and disability of an individual is socially constructed, contextual and environmental, and this is reflected in the WHO classification of functioning disability and health(World Health Organization, 2021). The course of MS is unpredictable and, as such, those individuals diagnosed with MS do accept that as a result of the diagnosis, they will become increasingly disabled or immobile over time. Bogart (2015) summarised the transformation of identity that occurs when someone is diagnosed with MS, and the journey to the eventual acceptance of their new identity. Disability identity is not within the scope of this research, and it was not something the participants were asked about. However, the participants in the present study all discuss elements of the process of acceptance of their diagnosis during their interviews and this challenged and called into question the validity of health narrative of disability around those who have been diagnosed with MS.

This section will discuss how these participants do not limit their involvement in activities because of their MS diagnosis or any perceived ‘disability’. The insight as to how those with MS see themselves and the context in which they view and understand the progression of their diagnosis can help us to appreciate the unique experience of those with MS and the role physical activity plays for them. Only then can the scope of physical activity options be tailored for those with MS to facilitate and encourage greater participation in activity overall for this population.

Disabled v Enabled.

For the participants in this study, MS is not an excuse to limit activity nor does being physically active have a medical focus, with its resulting focus on health success or failure. Instead of viewing themselves as challenged or disabled, these participants are positive, knowledgeable, empowered and enabled by being able to move, make decisions, adapt, and change, and are not using physical activity to slow their progression of MS. This is evident in their willingness to use alternatives, to accept that they might need to modify how they are active and to learn new skills.

There is no stasis, in fact, there is personal growth in having MS for these participants (for example, Angus refers to MS as being a huge “eye-opener” for him).

The participants in this study do not consider their MS to be limiting their participation in activities and this is a useful insight to help understand ways to encourage those with MS to be physically active. The participants here found ways to be “enabled”; they are willing to adapt so that they can continue being physically active. It is not all or nothing. The participants consider their health to be on a continuum, and they appear to accept an identity that encompasses having MS, but without necessarily wanting to “live the disease”. A study by Adamson et al. (2017) that explored disabled identity refers to those with MS using the exercises promoted by health providers “as a way of transforming (or maintaining) a desired identity as non-disabled or reinterpreting what disability means” (p. 468) rather than for simply using activity to improve their health outcomes. By emphasising physical activity prescriptions that focus on ‘fixing’ the body with exercise, individuals with MS may be impeded from cultivating a positive sense of their (disability) identity(Adamson et al., 2017). Despite ongoing efforts to improve overall health management of MS, most of those diagnosed develop mental health problems with rates of clinical depression affecting up to 50% of patients. As mental health is a major determinant of quality of life then the fostering of a positive sense of identity, in addition to physical wellbeing, is crucially important in the MS population(Barnard et al., 2020; Feinstein, 2011). The physical activity as medicine narrative discussed above potentially perpetuates a fixation on physical activity as being a way of avoiding future disability for those with MS and as a result, being inactive is identified with deteriorating mobility, increased symptoms, or relapse. While already coping with a highly unpredictable disease course, additional pressure on those with MS to be physically active to prevent further disability is an inherently problematic narrative for overall health(Adamson et al., 2017).

The relationship between physical activity and positive identity for those with MS, whether they view that identity as disabled or not, is complex and beyond the scope of this discussion. However, an examination of this cohort and how positively they value activity and the direct impact on both their identity and self-confidence merits thought, when considering how to promote physical activity as part of MS care and management. In this respect, practitioners could do well to change the narrative around physical activity and MS and acknowledge and accept how each of those people with MS views their diagnosis. In doing so, it is important to remember that MS is a gradual and unpredictable loss of function and participation and how a person identifies themselves during the course of MS will vary as they come to terms with the diagnosis(Bogart, 2015). For someone with MS, physical ability is fluid, there is no pre or post-diagnosis ability identity as there might be in a sudden onset event, such as that discussed by (Espernberger et al., 2021) in their study looking at physical activity determinants in people with stroke.

In conclusion, the constraint of physical activity to a form of medicine, through prescribing exercise as part of MS management or promoting it as a way of restoring past function or slowing the progression of disability, can also result in negative outcomes, in particular poor adherence, loss of intrinsic value, personal identity and autonomy(Adamson et al., 2022). The participants in the present study were specifically recruited because they were not currently following any clinical exercise prescription or set physical activity programme. As a result, the dominant insight from this study is that the value and role of physical activity for these participants goes well beyond health prescription or preventing the progression of disability, instead it emphasises the intrinsic values of physical activity through enjoyment, liberation, empowerment and building self-confidence. The discussion on intrinsic value naturally leads to the influence of a salutogenic model of health, which will be discussed in the next section, and how this can assist health practitioners and physical therapists reframe their approach to increase uptake and adherence to physical activity in this population.

Salutogenic Lens

As outlined in Chapter Three, the salutogenic model of health promotion advocates a proactive orientation to health and focuses on factors that maintain health rather than on factors that lower the risk of disease(Antonovsky, 1993). It has a focus on health maintenance and looks at what moves people towards the health end of a continuum between total ill-health (dis-ease) and total health (ease). For those who live with a diagnosis of MS, a model of health promotion that is fluid and supports and accepts the unpredictability of the symptoms of MS would seem a natural fit. The lived experiences shared by participants in this research, and the themes that arise from their experiences navigating physical activity and an MS diagnosis have some parallels with the Salutogeneic theory of health.

Managing or riding the wave – ownership, control, and support

When considering the interviews and themes in the previous chapter, the participants all express a positive relationship with physical activity, find meaning in the activity that they choose to do and have knowledge and resources that they utilise to manage the unpredictable path of an MS diagnosis. This resembles, in many ways, what Antonovsky describes as having a sense of coherence (SOC) or a personal coping resource that gives these participants the ability and capacity to respond to stressful situations as and when they arise SOC as defined by Antonovsky has three components – that a person understood what was happening to them, that they could manage the situation on their own, or with support, and that they had the ability to find meaning in the situation(Antonovsky, 1993).

The salutogenic model of health and how its influence can be seen in the way these participants engage with physical activity and what role it plays in the management of their diagnosis is best reflected in the theme of managing or riding the wave. This theme encapsulates SOC or belief that one has the internal resources to competently cope with a challenging situation. The participants in this study have both a thorough knowledge about MS and the ability to confidently convert that knowledge into action. They know that they have the support and wherewithal to cope and can find that support either in themselves, or from others, in times of need. Right throughout, participants mention the sense of control that they get when they are physically active, that is, they perceive to have control over themselves, their future, and their ability to assess and analyse their strengths and limitations.

Due to the uncertainty of an MS diagnosis, it has been found that those with MS may experience low self-efficacy and a perception of a lack of control (Backus, 2016; Reguera-García et al., 2020) and individuals who believe that they have control over their illness may adjust to and cope with MS more effectively(Riazi et al., 2004). Similar themes of ownership, control and support are also discussed by Hale et al. (2012) who conclude that long-term adherence to physical activity for people with MS requires: (i) choice of activity and (ii) control over the level of engagement, both of which facilitate a person's 'ownership' over the programme of activity, and (iii) support in their choice of programme with advice and encouragement over time by a physiotherapist(Hale et al., 2012). These are all elements that are present for the participants interviewed in this study.

These findings also align with the findings of a study by Barnard et al. (2020) where a sense of accomplishment and control were found to facilitate long-term adherence to activity for people with MS undertaking a multi-modal health intervention. Participants in that study spoke about the physical and psychosocial benefits that exercise provides, including the improved ability to deal with daily difficulties. Physical activity is often described by the present participants as making them feel good and this provides them with positive feedback. Furthermore, while fatigue was a barrier for some (for example, Margaret says sometimes she would just like to "blob"), these participants would inevitably be motivated to find a reason to move. The focus simply on an 'exercise' dosage inevitably turns to exercise becoming a task and resource intensive with the time required becoming a barrier to incorporating a specific level of activity into a busy life. This, I suggest, is where a change in how physical activity is framed is so important as evidenced by the participants in this study who, in choosing what, where, when and how much to be physically active were able to achieve a high level of activity with ease.

Similarly, a narrative study by Sikes et al. (2019) of those living with Paediatric Onset Multiple Sclerosis (POMS) identified experiences with and preferences for physical activity for those with POMS. These included preferences for a tailored or an individualised approach to a physical activity intervention, with increased access to knowledge for those living with POMS and learning about safe exercises and outcomes. In addition to knowledge, social engagement with others and peers with POMS was an important part of being physically active(Sikes et al., 2019). While not influenced by a salutogenic framework, the study by Sikes et al. (2019) mirrored the experiences of the participants in the extant study, and the meaningful role that physical activity played in their lives, as well as the participants' preferences and motivations to continue to be active. Furthermore, by facilitating an engagement with enjoyable and achievable activities in the present, we lay the foundation for continued physical activity engagement throughout life despite challenges that we may face, and this is very relevant to the experiences of those participants interviewed for this study.

Discussion on social engagement, "being normal" and self-efficacy also occur within Espernberger et al. (2021) where a review of all qualitative studies indicated five key factors that influenced physical activity levels for those who were recovering from or living with the after-effects of a stroke. Interestingly, rehabilitation from stroke was not one of those factors found to influence physical activity in stroke survivors, and likewise, the factor of rehabilitation is not evident for the participants of this study. Certainly, several participants saw the benefit of physical activity in improving the future (or being as normal as possible) but did not see the purpose of physical activity as a means to rehabilitate or regain those physical abilities they may have lost because of a relapse in MS symptoms. This is particularly relevant in the experiences shared by Ian and Angus who were very physically active before their MS diagnosis and who both were physically challenging themselves in other ways post-diagnosis. Angus was a rugby player and learned to swim, and Ian continued to trail run, mountain, and road cycle with a group (after re-learning to ride a bike with his vestibular issues) but also took up football and coaching his son's rugby team to keep physically active.

The lived experiences of the participants in the current study all present, in different ways, elements of the Antonovsky (1993) sense of coherence in that the participants' exhibit knowledge, confidence and ability to find resources to continue to be active and to also find the meaning or "why" to continue. That meaning can be for themselves, or for others, however, it is the combination of the SOC, together with social factors that foster a sense of control over the situation for these participants. In addition, and most importantly, for the success of these elements for present participants is the support or enabling by others for them to explore their solutions and to choose the physical activities that they partake in. As illustrated in Figure 1. enabling is the basis of all the elements or themes that follow. McCuaig and Quennerstedt (2016) explore these social aspects of salutogenesis in their discussion around salutogenically orientated physical education programmes for young people and in doing so refer at length to Antonovsky's metaphor of public health being a river. Not only do we need to ensure a swimmer in that river can swim, but that the conditions in the river are conducive to that person staying afloat. In essence, understanding the social construct that surrounds an individual is as important as looking after that individual's health. Supporting and working with those people with MS to seek and obtain knowledge, to present and support them in a wide range of activities, and therefore empower them to choose how to be active, will help that person to develop the tools to be able to cope with whatever or wherever their "river" may flow. This is the insight gained from the present participants who enjoy and find meaning in every aspect of being physically active and are prepared always to manage or adapt to the unpredictability of MS, both now and in the future.

Conclusion

This discussion has highlighted the importance for people living with MS to participate in physical activities of their own choosing, continuing to be active socially in those activities, with both their peers and with others who were diagnosed with MS. The discussion further illuminates the way participants navigate physical activity narratives outside the boundaries of the prescription of exercise, and the determination of the intensity and amount of time they should spend being active. It emphasises that those people with MS value the importance of finding activities they enjoy, that challenge them, make them feel accomplished and give positive social and emotional feedback. The medical narratives for rehabilitation or delaying the onset of physical disability were also not a consideration for these participants when choosing activities; instead, the analysis shows that what drove them was finding meaning behind activity, moving forward, learning to manage energy resources, and relishing how physical activity made them feel. Participants were willing to adapt or modify activities to maintain those positive values of exercise; it was worth the while to them to continue to be physically active.

The findings in this study suggest that people with MS are knowledgeable about their diagnosis and, consequently, the physical activity resources available to them. This knowledge provides them with a sense of control and choice over their long-term health behaviour and outcomes. It also gives them a sense of pride and accomplishment and an element of 'normality' which they cherish. This study also indicates that a salutogenic health construct is intuitively utilised by these participants though gaining knowledge and understanding the situation, maintaining a positive life orientation, seeing the intrinsic value in physical activity, adapting where necessary and moving themselves toward greater health outcomes. Therefore, a shift toward the salutogenic method of health promotion would be beneficial for with those with MS to encourage longer term engagement in physical activity for this population and recommendations as to how this can be achieved are in the following chapter.

CHAPTER EIGHT – CONCLUSION AND RECOMMENDATIONS

An analysis of the interviews, and the themes that evolved, confirm that current physical activity and health narratives are not resonating with the people in this population. The overwhelming majority of physical activity experiences for the individuals in this study were self-selected, meaningful and positive. All participants had an in-depth knowledge about their condition, they were self-analytical and knew how to manage themselves within the bounds of the diagnosis. Furthermore, the accomplishment they got from participating in a variety of 'unprescribed' forms of activity encouraged these participants to continue with these activities over the long term. Additionally, all participants had formulated plans and considered alternatives or mobility aids to continue to be physically active into the future. Each participant had propagated their own knowledge resource, and when additional advice was required, they were able to obtain guidance from other people that was tailored to their needs, abilities, and preferences. While negotiating different diagnoses, mobility limitations, ages and contexts, these participants shared beliefs, experiences, and motivations which, while not generalisable, are informative for encouraging increased physical activity in this population.

The themes of knowing, meaning, managing, and enabling that developed through analysis represent an understanding of how these participants continue to be physically active. A diversity of interests, abilities, and symptoms of MS, and the relatively young age at which MS is diagnosed, requires a tailored, person-oriented physical activity programme instead of a one-size-fits-all prescribed approach. Guidance gained from these themes may assist health professionals in increasing levels of physical activity in those with MS over the longer term.

Firstly, and the most compelling insight from this study, is the realisation that for those with MS, it is a lifetime of symptom management, reassessment, and resilience. Right from diagnosis, the participants here researched, self-assessed and investigated options to manage their condition and the effort taken in the pursuit of knowledge cannot be overestimated. Therefore, physical activity recommendations, which are goal-orientated, do not synergise well with the lived experience of MS. Furthermore, promoting physical activity solely to improve symptoms or rehabilitate lost mobility is facile. To that end any recommendations for exercise and physical activity for those with MS should include a range of options that consider individual differences at every level of ability, and which encourage the wider benefits of activity. Health practitioners should focus on communicating with patients about MS and what they have learned about their condition, encourage them to be open to all opportunities for movement and provide access to practical resources where required. The participants in this study maintained physical activity through their own research and by being unrest in the activities they would consider therefore, they had options and choices, and in doing so took control of their health outcomes, albeit with support and guidance.

Secondly, finding a purpose and meaning in physical activity, outside of the health benefits, breaks the pattern of sedentary behaviour and provides a natural platform for participation in further exercise modalities. This idea that something is better than nothing – “move it or lose it” as termed by the participants in this study, the knowledge and understanding of why movement is so important, and being able to get on with it in a way that is not threatening or difficult, is a solution to increasing physical activity in those people with MS. The insight from these participants as to the meaning and purpose behind why and how they are physically active should encourage clinicians and health professionals to undertake wider conversations about activities for those with MS. It is crucial to be open to discussing and considering all avenues of movement with people with MS and assist them by providing the knowledge and support that patients need to make autonomous, confident decisions about the range of physical activities they will continue to participate in for their future health benefits.

Finally, health professionals when discussing physical activity with people with MS can promote and enable positive action to increase levels of physical activity through:

- empowering patients to seek out knowledge,
- encouraging them to monitor and evaluate their intrinsic response to physical activities,
- guiding them to find a meaning or reason to be active,
- providing them with the tools and support to cope with change or restricted ability when required, or directing them to another health professional who can assist, and
- supporting them with a plan of action in terms of what, when, where, and how they participate.

In essence, health professionals must work to enable those with MS to become both competent and able swimmers in the river of life, while ensuring the water is as safe and as buoyant as possible.

Strengths and Limitations

The findings, themes and recommendations of this study must be considered in light of the following strengths and limitations.

Firstly, this was an in-depth narrative exploration of eight people with MS, who continued to be physically active. Many in-depth studies in this area are of single participants and having eight different views and perspectives makes the thematic findings robust, while the lower number of participants means the data obtained was rich and has depth.

The reflexive analysis process and my positionality as an outsider resulted in a semi-structured, open-ended and naïve questioning, whereby the participant was deemed to be the expert. This was a strength, I believe, as participants had the space to traverse and explain experiences in detail. Furthermore, they confirmed they felt safe, accepted, listened to and confident. Throughout each interview, I continued to actively reflect on my knowledge and role in the data collection process so that I remained curious and accepting of the participants' experiences.

The use of a critical friend played an important role in normalising ongoing reflexivity and ensured that self-evaluation continued right throughout the interview process. The use of a critical friend also provided a trusted platform from which to gain insights into the research setting and to reveal further unexamined assumptions made of myself and the participants (Lees et al., 2022). This was an important part of being able to connect and build a relationship quickly with my participants and I believe played a large role in the participants being open and communicative with me about their experiences with MS and physical activity.

The importance of reassessing and re-evaluating my knowledge as I interacted with each participant was reflected in how I framed the interactions with participants throughout the interview process. To that end, having the interviews occur in quick succession was an advantage as my knowledge of MS remained limited while I processed and transcribed the audio.

The influence of the Salutogenic framework, with its positive orientation, was a strength of the study and resulted in a focus on those actions taken by participants that moved them towards long term engagement in physical activity. Therefore, when participants shared the way in which they had overcome certain physical or cognitive challenges, it occurred without these experiences having a negative orientation.

A further strength was the minimum level of activity requirement of 2.5 MET which resulted in the involvement of participants who were active in a wide variety of ways. This meant that experiences and contextual backgrounds were varied, with the role of physical activity for each participant being different, which therefore enhanced the richness of the data.

All but one of the interviews were conducted online via Microsoft Teams. Initially, this was because the study began within the COVID-19 restrictions that were imposed in New Zealand (and more particularly Auckland where this research is based) during the period 2020 to 2022 and it was considered that conducting online interviews might have been a limitation. However, on reflection, this was a strength. Familiarity with online methods of contact during the lockdown period in New Zealand meant that participants were comfortable speaking online and, additionally, interviews could be whenever the participants were available, without any time constraints. The availability and familiarity with technology due to COVID restrictions meant once participants had expressed interest, recruitment and interviews were arranged quickly and efficiently. This had a further benefit of a very quick turnaround in interview transcription and that the interviewer's positionality as an outsider was not compromised by a lengthy recruitment and interview process.

The study was limited in that only those who were enthusiastic and had positive physical activity experiences were likely to take part. The method of recruitment also required action on the participants' behalf to contact the researcher directly, and whilst some suggested their level of activity may be 'too low', each participant was willing and keen to share their life experience for the benefit of others.

While the researcher's positionality as an outsider was a strength, as referred to above, it was also a weakness in that the naivete of the understanding of the MS diagnosis meant that certain narratives, particularly around disability, were potentially underexplored in the interview. These narratives became clear as the analysis progressed, and it is an area of research that deserves further exploration within this same methodology and utilising the Salutogenic framework. Likewise, the ways that those with MS combine pharmacological and lifestyle treatments require further research, as does the concept of patient-led care, however, this would require additional questioning and wider recruitment to those who were currently utilising an exercise programme recommended by a physiotherapist.

This study enabled an exploration of the ways in which these participants with MS continued to be physically active, in addition to managing everyday life with an unpredictable health condition. I am grateful to each participant for being so open with this study and sharing their knowledge so that those who design and promote physical activity can learn what it is like to live and be active with MS. I hope this thesis can contribute to a better understanding of the context and nuance behind how those with MS feel, think and interact with physical activity and that, for them, being active is a whole lot more than just bodily movement and energy expenditure.

> *Not every day is kind of like, you know, razzmatazz and all of that and flying the banner but um I try and think, you know, why not? Why not celebrate the day and get on with it and yeah, cause it's kinda life's too short. It's too short, you know.* Margaret, 61

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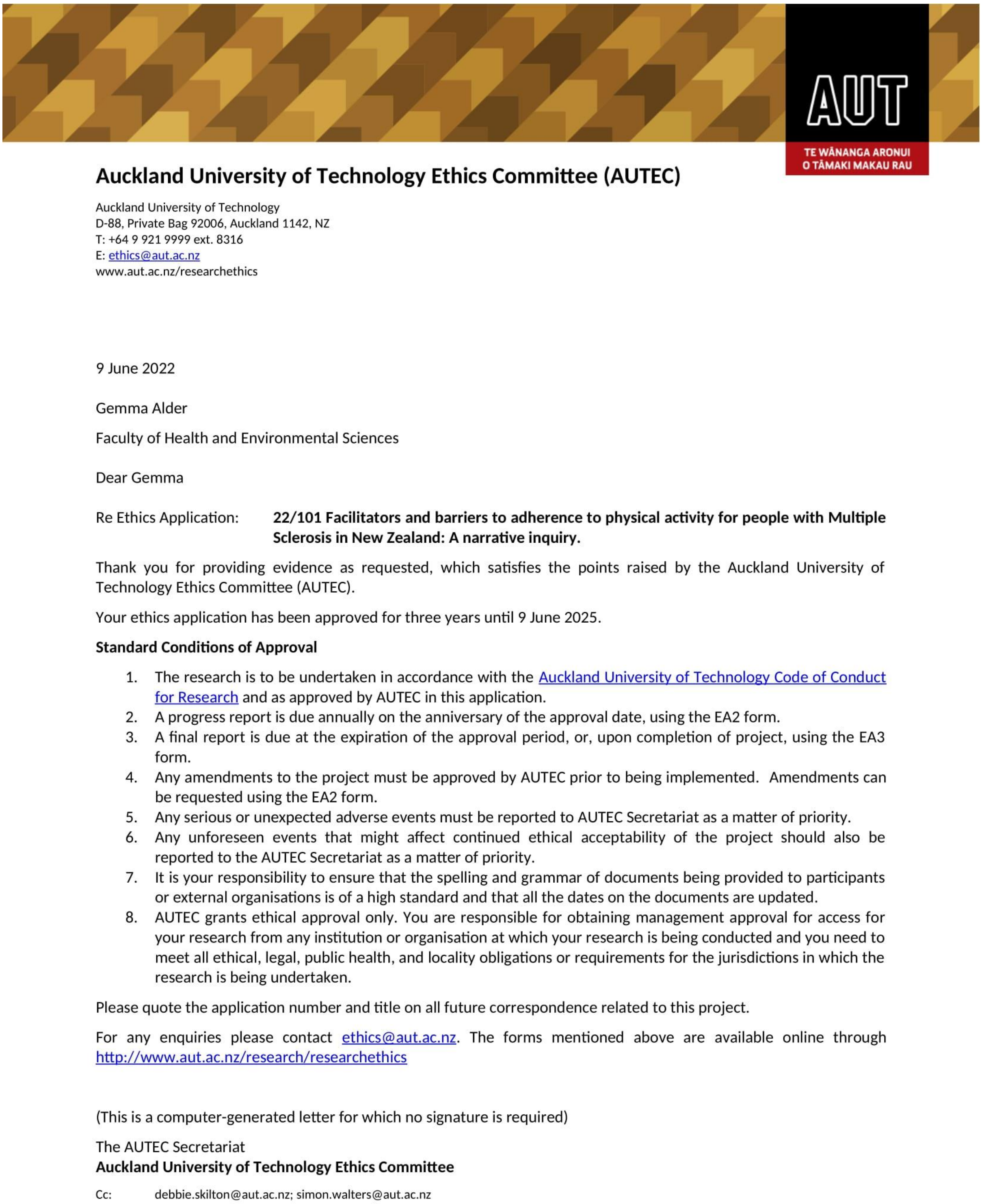
APPENDIX A – ETHICS APPROVAL



Auckland University of Technology Ethics Committee (AUTEC)

Auckland University of Technology
D-88, Private Bag 92006, Auckland 1142, NZ
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9 June 2022

Gemma Alder

Faculty of Health and Environmental Sciences

Dear Gemma

Re Ethics Application: **22/101 Facilitators and barriers to adherence to physical activity for people with Multiple Sclerosis in New Zealand: A narrative inquiry.**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 9 June 2025.

Standard Conditions of Approval

1. The research is to be undertaken in accordance with the Auckland University of Technology Code of Conduct for Research and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard and that all the dates on the documents are updated.
8. AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted and you need to meet all ethical, legal, public health, and locality obligations or requirements for the jurisdictions in which the research is being undertaken.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through http://www.aut.ac.nz/research/researchethics

(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

Cc: debbie.skilton@aut.ac.nz; simon.walters@aut.ac.nz

APPENDIX B – INFORMATION SHEET

Participant Information Sheet

Date Information Sheet Produced:

2 March 2022

Project Title

Facilitators and barriers to adherence to a physical activity for people with Multiple Sclerosis (MS) in New Zealand: A narrative inquiry.

An Invitation

Kia Ora. My name is Debbie Skilton, and I am a post graduate Sport & Exercise student working towards my MPhil in Sport & Exercise. I'd like to invite you to participate in a narrative study to explore the experience of physical activity from your point of view, as a person living with Multiple Sclerosis, within the environment that you live. I would like to gather a rich personal experience of MS and discover and analyse your experience of physical activity, in what ways you keep active and why. The research will be proactive in nature and capture information about positive habits.

Your participation in this project is entirely voluntary (your choice). You can withdraw at any time.

What is the purpose of this research?

The purpose of this research is to identify the barriers and facilitators to physical activity from the perspective of people with MS in New Zealand, with a view to identifying the motivations and experiences of those people diagnosed with MS who are currently physically active. The information gained will guide clinicians and exercise professionals to design prescribe, promote, and deliver physical activity programmes and support services that meet the needs and challenges of those with MS and to maximise their health outcomes.

The findings of this research may be used for academic publications and presentations.

How was I identified and why am I being invited to participate in this research?

You will have been involved in previous studies through the Health & Rehabilitation Research Institute (HRRI) and consented to be contacted for further related research or you would have seen advertising either physically or online and contacted the researcher involved in this study.

You are eligible for this study if you meet the following criteria:

- You were diagnosed with MS more than 3 months ago
- Your MS is currently stable, and your symptoms are controlled
- You are physically active. The level of physical activity needed to participate is all activities beyond that which would be considered

sedentary or rest. This encompasses completion of household chores, engaging in participatory activities with others and includes modes of self-transportation like walking and wheeling.

- You are not an elite athlete
- You are not undertaking any structured rehabilitation programmes
- You do not have any cognitive or communication difficulties that prevent you from taking part and you are also able to participate and communicate in the English language.

How do I agree to participate in this research?

You can contact us on the details below if you wish to take part in the study. You will need to undergo a brief screening assessment over the telephone for us to determine whether you are eligible to participate. Prior to taking part, you will need to complete a consent form. You will have time to consider if you wish to take part in this study and ask any questions before providing consent to take part. A consent form is attached to this information sheet.

Your participation in this research is voluntary (it is your choice) and whether you choose to participate will neither advantage nor disadvantage you. You can withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

The project involves participation in a one-on-one interview about your experience with physical activity. The interview will occur either in person or online via a digital platform. If you choose to take part, the interview will take approximately 1 hour. The interview will be audio-taped, and notes will be taken during your interview.

What are the discomforts and risks?

The research concentrates on proactive actions and positive physical activity habits so there will not be any discomfort or risk in sharing your experiences.

You may find the interview uncomfortable at times, particularly if your experience with physical activity has not always been a positive one. However, it is important to us that you are honest about your experiences.

How will these discomforts and risks be alleviated?

You can choose not to talk in depth about negative experiences if they cause you distress, but we do ask you to be open about your experience of physical activity and to give suggestions about improvements and support requirements. AUT Health Counselling and Wellbeing is able to offer three free sessions of confidential counselling support for adult participants within the Auckland area in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research and are not for other general counselling needs. To access these services, you will need to:

- drop into our centres at WB219 or AS104 or phone 921 9992 City Campus or 921 9998 North Shore campus to make an appointment. Appointments for South Campus can be made by calling 921 9992
- let the receptionist know that you are a research participant, and provide the title of my research and my name and contact details as given in this Information Sheet

Alternatively, the research team can assist you finding appropriate support through your own General Practitioner.

You can find out more information about AUT counsellors and counselling on http://www.aut.ac.nz/being-a-student/current-postgraduates/your-health-and-wellbeing/counselling.

What are the benefits?

While there are no immediate benefits to you personally for taking part in this study, you will be sharing your experience and thereby contributing to information that could provide better experiences for others with respect to physical activity.

It will help my peers in that it will provide rich contextual background to understand and identifying the motivations and experiences of those people diagnosed with MS who are currently physically active.

The information obtained will help exercise specialists to design, prescribe, promote, and deliver tailored physical activity programmes that meet the needs and challenges of those with MS and to maximise their health outcomes.

The study will help me as it will help me obtain my qualification.

How will my privacy be protected?

Interviews and recordings (and any notes taken) will be de-identified and confidential, will only be available to the research team. This de-identified data will be held on AUT premises for a period of 6 years, after which time it will be destroyed.

What are the costs of participating in this research?

The only cost to you is your time, which will be approximately 1 hour of interviewing with a researcher. The researcher will meet you at an AUT campus or and AUT affiliated location that is private and convenient to you or online using a digital platform. If there are any travel costs, then these will be reimbursed.

What opportunity do I have to consider this invitation?

We would like to know whether you wish to take part within 14 days of receiving this information sheet.

Will I receive feedback on the results of this research?

You can choose to receive a summary of the findings of this research, and you will have an opportunity to view and correct any transcript. You will get the summary when the study is completed, and the transcript will be discussed with you once it is fully transcribed.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Gemma Alder, *gemma.alder@aut.ac.nz*, (+649) 921 9999 ext 7815

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, *ethics@aut.ac.nz* , (+649) 921 9999 ext 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Debbie Skilton, debbie.skilton@aut.ac.nz

Project Supervisor Contact Details:

Gemma Alder, gemma.alder@aut.ac.nz 09 921 9999 ext 7815

Approved by the Auckland University of Technology Ethics Committee on 9 June 2022, AUTEC Reference number 22/101.

APPENDIX C – CONSENT FORM

AUT
TE WĀNANGA ARONUI
O TĀMAKI MAKAU RAU

Consent Form

Project title: ***Facilitators and barriers to adherence to a physical activity for people with Multiple Sclerosis (MS) in New Zealand: A narrative inquiry.***

Project Supervisor: ***Gemma Alder***

Researcher: ***Debbie Skilton***

1. I have read and understood the information provided about this research project in the Information Sheet dated 2 March 2022.
2. I have had an opportunity to ask questions and to have them answered.
3. I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
4. I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
5. I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
6. I agree to take part in this research.
7. I wish to receive a summary of the research findings (please tick one): Yes £ No £

Participant's signature: ....
....

Participant's name: ....
....

Participant's Contact Details (if appropriate) :

....
....
....

Date:

Approved by the Auckland University of Technology Ethics Committee on 9 June 2022, AUTEC Reference number 22/101

APPENDIX D – INTERVIEW GUIDE

Pre-interview tasks:

- Email introduction
- Offer a trial run for the video conferencing software before the session if requested
- Send a session link for the online video conferencing software (generated by the researcher)
- Make contingency plans for what to do if video link fails
- Ensure strong internet connection, preferably fast broadband
- Check audio/video function before the session

Set up the environment:

- A quiet, well-lit, and private room to ensure participant's privacy is maintained
- On the day, ensure there is good internet connection and technology set up; Test audio/video connection and adjust setting if needed before calling the participant.
- Ensure email, online, and phone notifications are turned off for the duration of the session
- Check surroundings, lighting, noise, etc.
- Invite the participant by saying 'kia ora or hello' followed by 'can you hear and see me clearly?'
- Introduce yourself and explain your personal and clinical background, purpose of this research and your role in it.
- Enquire about how the participant is feeling and any considerations and practices participants would like you to follow
- Invite the whānau to be present during the session if required.
- Go over the procedure for disconnection.
- Start the recording
- Reiterate the introduction and that the conversation will be recorded and that participants can stop the interview midway or decline to continue if they feel unsafe or uncomfortable
- Inform the participant when you are occupied i.e., taking notes, or reading
- Give participant a scan of the room to confirm privacy and ask participant to give you a scan of the room in return.

Sample Questions (to be further refined).

1. Please give me a background of your diagnosis of MS, how it came about, and what has happened since.

2. In what ways are you physically active? How does this compare to before diagnosis?

3. How does physical activity play a role in your day? On days that it does not, why might this be the case?

4. What does a day look like for you? Is every day the same?

5. Does anything you do during your day benefit as a result of your physical activity behaviour? How does this make you feel?

6. Does anyone support your opinions and decisions about being physically active? How? How do you feel in this regard?

7. Do you engage in physical activity with anyone else? What does this look like? What does this mean for you?

8. Is there anything else you would like to share about your physical activity participation?

APPENDIX E – FINAL SAMPLE QUESTIONS

Sample Questions / Interview Guide

1. Tell me about yourself (how old are you, when were you diagnosed, MS diagnosis, symptoms, how it progressed, how and why the participant sought medical advice/diagnosis, what has happened since)

2. What does a day look like for you? What's the first thing you do in your day?

3. How motivated are you to move daily? *Movement or physical activity is participatory, doing things for yourself, walking the dog, gardening, hanging washing etc. Something more than sedentary.*

4. How confident are you that you will continue to move daily in this way?

5. Has this changed over the years? Are you moving more? Or less? Or about the same?

6. Why do you like to move daily? What encourages you to move? What role does movement play in your day? Is every day the same? And if it doesn't play such a role on some days, is there a reason why?

7. Who or what is the wind beneath your wings? Your biggest supporter? What do they do and how does that make you feel?

8. Is there anyone that you connect with to do things outside the home? What does this look like? What does this mean for you? How does it make you feel?

9. Tell me in what ways is maintaining a level of physical activity worth the while?

10. Is there anything else you would like to share about your daily movement and participation in activities?