Factors influencing Motivation and Retention of people with Multiple Sclerosis in Exercise Activity: a qualitative study

Mohini Sacha

This thesis is presented in partial fulfillment of the requirements for the degree of Bachelor of Psychology (Honours), Murdoch University, 2017
Declaration

I declare that this thesis is my own account of my research and contains as its main content work that has not previously been submitted for a degree at any tertiary educational institution.

Signed: ............................................

Mohini Sacha
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Finally, I want to thank my daughter Tara for her unwavering, steady support as well as my friends for their encouragement.
Factors influencing Motivation and Retention of people with Multiple Sclerosis in Exercise Activity: a qualitative study

Abstract

People with Multiple Sclerosis (MS) experience barriers to exercise participation, resulting in low exercise engagement and high levels of dropouts. Consequently, the aim of this study was to examine the psychosocial factors that predict participation and retention in exercise activity and support programmes for people with MS. Fifteen participants diagnosed with MS (ages 42-73, twelve women and three men) were recruited for semi-structured interviews through the Multiple Sclerosis society of Western Australia (MSWA). Data was analysed using inductive thematic analysis as well as the frameworks of social cognitive theory, theory of planned behaviour, self-determination theory and job embeddedness theory. This study identified three themes, attitudes about purpose, improved wellbeing and an opportunity for connection and support that were found to influence motivations to exercise as well as enhancing participation in exercise activity. The combined forces of these factors together with individual characteristics influenced a person’s embeddedness or attachment to their exercise activity, and their decision of whether to stay or leave. These findings are valuable, as it will assist to inform future clinical interventions of factors implicated in retention and what they need to address in order to retain a high number of participants in exercise programmes.
Factors influencing Motivation and Retention of people with Multiple Sclerosis in Exercise Activity: a qualitative study

Multiple Sclerosis (MS) is a progressive chronic disease of the central nervous system affecting 23,700 Australians and more than 2.5 million people worldwide (Australian Bureau of Statistics, ABS, 2012). MS is characterised by the myelin sheaths, the insulating cover of the nerve cells, becoming damaged and scarred (sclerosis in Greek). This damage interferes with the transmission of nerve impulses within the brain, spinal chord, and optic nerves affecting motor, sensory and cognitive functions. MS is most prevalent in higher socio-economic countries and reported being three times more common in women than in men (ABS, 2012; World Health Organization, WHO, 2008). The onset of MS is generally between 20-40 years of age (Multiple Sclerosis International Federation, MSIF, 2017). Presenting symptoms are muscular weakness and dysfunction, disturbed balance, fatigue and sensory problems, visual disturbances, bowel and bladder problems, pain and cognitive dysfunction such as depression, memory loss and concentration problems (WHO, 2008). These symptoms are unpredictable and commonly progress overtime resulting in devastating consequences for the individual’s physical and social activities as well as the quality of life (MSIF, 2017). There are four main types of MS; Relapsing-remitting MS (RR) is where unpredictable attacks of symptoms (relapses) occur, with symptom-free periods (remissions) in-between. Primary-progressive MS (PP) relates to a slow onset and worsening of symptoms with no relapses or remissions. Secondary-progressive MS (SP) involves continuous relapses with no definite remissions in-between. Finally, progressive-relapsing MS (PR) show a steady worsening and neurologic decline with acute relapses and no remissions (MSIF, 2017). The aetiology of MS is still unknown but suggested factors are a virus, genetic disposition or environmental exposures (MSIF, 2017). There is no known cure for MS with only a limited number of drug treatments aimed at relieving symptoms. Therefore people with
MS often seek treatments within alternative modalities with the most commonly used being diet and nutrition, herbal medicine, acupuncture, massage and homeopathy (WHO, 2008).

**Exercise and MS**

A growing body of evidence suggests that exercise improve daily functioning, participation, health and quality of life in people with MS (Khan, & Amatya, 2017; Learmonth, & Motl, 2016). However, clinical best practice in MS management concerning exercise is not clear. *Exercise* is here referred to as a “planned, structured and repetitive physical activity undertaken overtime with a goal of maintaining or improving physical fitness” (Caspersen, Powell, & Christenson, 1985). A meta-analysis by Khan & Atmaya (2017) found high-quality evidence in support of exercise therapy for enhanced activity, participation and reduction in fatigue, compared to the low (e.g., dietary, cognitive and memory treatment) or moderate (e.g., strength training, CBT) evidence for other multi-disciplinary interventions. Research confirms the benefits of exercise in managing a variety of MS symptoms (Learmonth & Motl, 2016). Exercise programmes have demonstrated improvements in fatigue, muscular strength, balance, depression, aerobic capacity, walking mobility and quality of life (Ensari, Motl, & Pilutti, 2014; Latimer-Cheung et al., 2013; Motl, 2014; Motl & Gosney, 2008; Pilutti, Greenlee, Motl, Nickrent, & Petruzzello, 2013; Schmidt & Wonneberger, 2014; Snook & Motl, 2009). Therefore, exercise training is today considered to be the single most effective non-pharmacological treatment for MS and is part of many effective rehabilitation programmes (Dalgas & Stenager, 2014; Motl, Sandroff, & DeLuca, 2016).

There has previously been uncertainty due to findings that MS symptoms have been perceived to be worsened by exercise, an experience that may turn into a barrier for the individual to further exercise (Kayes et al., 2011; Plow, Resnik, & Allen, 2009; Simmons, Ponsonby, van der Mei, & Sheridan, 2004). However, current research suggests that
negative consequences of physical exercise are rare and that exercise for people with MS is not only safe, but is required to uphold and maintain healthy physical functioning (Pilutti, Platta, Motl, & Latimer-Cheung, 2014). Alternatively, Smith, Hale, Olson & Schneiders (2009) found that persons with MS experienced a critical point or “edge” during exercise. Dependent on whether the participant managed to stop the exercise in time or moved beyond that edge, the participants experienced either positive (healthy tiredness, positive feelings and physical improvements) or negative (unhealthy tiredness, feeling worse) perceptions of fatigue. Furthermore, physical exercise generally declines as the disease progress and may lead to an increased risk for secondary conditions. This could include diabetes, obesity and cardiovascular disease as well as depression, anxiety, social isolation and reduced general wellbeing (Backus, 2016; Motl & McAuley, 2009; Stroud & Minahan, 2009; Vanner, Block, Christodoulou, Horowitz, & Krupp, 2008).

Learmonth & Motl (2016) conducted a qualitative systematic review and found that some of the most common perceived positive consequences of exercise were to be able to maintain their physical functions, an opportunity for added social participation as well as providing feelings of control and self-management. The most commonly perceived negative consequences were added fatigue, frustration and feelings of loss of control. 

Factors influencing exercise participation

Despite well-known benefits of physical activity for people with MS, engagement in exercise is low (22%) compared to other chronic disease groups and the general population (Backus, 2016; Klaren, Motl, Dlugonski, Sandroff, & Pilutti, 2013; Marrie et al., 2009; Motl, McAuley, & Snook, 2005). Furthermore, evidence reveals that people with MS struggle to maintain exercise participation resulting in high levels of dropouts (Pilutti et al., 2014; Rampello et al., 2007). Consequently, there has recently been an increased interest in understanding factors that influence exercise participation for people with MS. Christensen, Brincks, Schnieber & Sorensen (2016) conducted a qualitative
meta-synthesis identifying factors influencing *intentions to exercise* and *the execution of exercise* for persons with MS. They found social support, professional support and outcome expectancies as the primary motivating factors. Further, Newitt, Barnett & Crowe (2015) conducted a review looking at factors influencing physical activity for people with neuro-musculoskeletal conditions including MS. They found *human functioning factors* (e.g. maintaining independence, weight and functioning, and preventing secondary conditions), *personal factors* (e.g. feelings of enjoyment, feeling good and normal, goal setting and achievement, motivation and optimism) as well as *environmental factors* (e.g. social support), as leading motivators for exercise.

**Barriers and facilitators in relation to exercise**

Inactivity in people with MS depends on several variables rather than a simple lack of interest. The majority of people with MS believe that physical exercise would be beneficial to their health and would be interested in starting an exercise regime (Learmonth, & Motl, 2016, Vanner et al., 2008). However, people with MS are faced with a set of unique determinants in addition to commonly known barriers reported by the general population. The Physical Activity for people with Disabilities (PAD) framework recognises the critical role of barriers and facilitators in explaining physical activity behaviour among people with a disability (van der Ploeg et al., 2004). Personal barriers may be their physical impairment (e.g. level of fatigue, pain, mobility, heat sensitivity), a significant determinant of physical activity, or behavioural and cognitive factors (e.g. level of self-efficacy, fear of worsening of symptoms, depression, anxiety, outcome expectations). Environmental barriers are the external factors (e.g. accessibility to transport and disabled facilities with knowledgeable professionals, affordability, lack of appropriate information or time), including social influences (e.g. social support, perceived negative attitudes of from others), (Asano, Duquette, Andersen, Lapierre, & Mayo, 2013; Backus, 2016; Kayes et al., 2011). Facilitators are often the opposite of these
barriers. For example, having enough time, money, social support, self-efficacy, positive coping styles, feeling of accomplishment, self-regulation, professional support, and positive outcome expectations facilitates exercise participation (Christensen et al., 2016; Learmonth & Motl, 2016). Ultimately, the aim is to overcome these barriers to exercise and improve adherence and quality of life for people with MS.

**Theoretical Framework**

To successfully implement health interventions, to be able to explain, predict and improve self-management in people with disabilities, evidence-based theories of health behaviour change is required (Dunn & Elliott, 2008). There have been critics voicing the lack of a theoretical basis in research of exercise behaviour in people with chronic disease (Tulloch et al., 2009). Promoting adherence to exercise is a challenge for service providers (Portnoy, Scott-Sheldon, Johnson, & Carey, 2008), and requires the understanding of motivational processes underlying these behaviours. Motivation has been shown to be a critical factor influencing participation and continued exercise (Teixeira, Carraca, Markland, Silva, & Ryan, 2012). Motivation can be defined as “the internal and/or external forces that produce the initiation, direction, intensity and persistence of a behaviour” (Vallerand, 2004). Motivational theories have been shown to be useful instruments in motivating and engaging participants in exercise programmes (Hagger, & Chatzisarantis, 2009). Exercise behaviours have generally been understood to be influenced by multifaceted factors that cannot be covered by one theory alone (Bauman, Sallis, Dzewaltowski, & Owen, 2002). Therefore integrated models of theoretical approaches have become increasingly common (Baranowski, Anderson, & Carmack, 1998; French et al., 2012; Hagger, M. & Chatzisarantis, N., 2016). While findings from these theories often show overlapping conceptual constructs that are closely related, they are not clearly differentiated (e.g. self-efficacy and perceived behavioural control), (Hagger, & Chatzisarantis, 2009). On this basis, the present study will use three
well-established theoretical perspectives that have been shown useful in predicting exercise adherence as well as increasing exercise participation, social cognitive theory (Bandura, 1997), theory of planned behaviour (Ajzen, 1991; Hagger, Chatzisarantis, & Biddle, 2002; Symons Downs, 2005) and self-determination theory (Deci, & Ryan, 1985, 2000). Furthermore, one theory borrowed from the field of organizational psychology, job embeddedness theory (Mitchell & Lee, 2001) will be used.

**Social Cognitive Theory** (SCT; Bandura, 1989a) explains behaviour by a mechanism called reciprocal determinism, a triadic dynamic, interactive process between personal, behavioural and environmental factors. It suggests that people acquire behaviours and skills by performing them, getting reinforced for doing them and by observing others. These observed and direct experiences then influence the development of different expectations. **Self-efficacy** relates to the confidence in one’s ability to perform a behaviour successfully to reach a specific goal, despite possible barriers (Bandura, 1997), and **outcome expectations** concern the consequences of one’s behaviour. Other constructs involved in SCT are modeling, locus of control, self-regulation and perceived barriers and facilitators (Bandura, 1989b, 1991, 2004).

**Theory of Planned Behaviour** (TPB; Ajzen, 1985, 1991) on the other hand state that **intention** is the best proximal predictor of behaviour by mediating the outcome of three belief based behavioural perceptions such as attitudes, subjective norms and perceived behavioural control. **Attitudes** toward behaviour refer to an individual’s evaluation of the act including beliefs, motivations, preferences and the perceived expected outcomes of that action. **Subjective norms** assess the social influence from others to perform a specific behaviour, for example their perceptions of whether their friends, family or others expect them to perform a specific behaviour (injunctive social norm), or whether these others perform the behaviour (descriptive social norm). These norms derive from normative attitudes and the perception of whether the chosen behaviour attracts others approval or
disapproval. *Perceived behavioural control* originated in Bandura's self-efficacy construct according to Ajzen (1991) and relates to one's conviction of being able to successfully carry out a behaviour to produce an outcome, as well as the ease or difficulty of doing so. The more favourable these attitudes and norms are that influence the behavioural intention, the higher is the likelihood the behaviour will be enacted according to TPB.

*Self-Determination Theory* (SDT; Deci, & Ryan, 1985, 2000) is a theory of human motivation, psychological development and wellness. It suggests a different approach to motivation with a focus on the quality, rather than the amount of motivation in a particular context, as well as including environmental factors that influence that motivation. A central concept in this theory is the distinction between *Autonomous (self-determined) motivation* that occurs when one feels a sense of autonomy and personal choice, versus *controlled motivation* which is experienced as being under the control or coercion by external forces (Hagger & Chatzisarantis, 2009). Research has demonstrated that autonomous motivation predicts adherence and persistence and is required for efficient performance while also being correlated with psychological health (Deci, & Ryan, 2008a, 2008b). It further argues that interpersonal contexts that provide the satisfaction of three basic psychological needs such as autonomy, competence and relatedness increase autonomous motivation, a fact proven by extensive research (Deci, & Ryan, 2008a, 2008b). Accordingly, the degrees to which these psychological needs are satisfied or unsupported affect both the strength and type of motivation. *Autonomy* refers to the experience of choice and self-determination, *competence* to the need to efficiently interact with the environment and *relatedness* to the experience of when supportive and satisfying relationships are met. In STD motivation is viewed as a continuum from *amotivation* (lack of motivation), via *extrinsic (external) motivation*, to *intrinsic (internal) motivation*. Intrinsic motivation is self-generated based on interest and satisfaction in contrast to extrinsic motivation that is generated from the outside and related to specific outcomes.
(Ryan & Deci, 2000). Therefore intrinsic motivation is more likely to inspire a behaviour change although both of these motives are implicated simultaneously in most behaviours to varying degrees (Brooks et al., 2017; Joseph, Daniel, Thind, Benitez, & Pekmezi, 2016).

*Job Embeddedness Theory* (JET; Mitchell & Lee, 2001) examines the collection of forces that influence employee retention by assessing three different dimensions. They are *links* or connections to other people and activities, perceptions of one’s fit with or compatibility and comfort with the organisation, and beliefs of what one would have to *sacrifice* or give up if leaving the job. These constructs are essential both on-the-job and off-the-job. Mitchell and colleagues (Mitchell, Holtom, Lee, Sablynski & Erez, 2001) describe embeddedness as a net or web in which a person can become stuck. They propose that the more complex network of connections a person has to the community and organisation, the more embedded a person is and consequently less likely to leave, in contrast to those who have fewer connections. So, for example, a person with high embeddedness is someone who fits well with the organisation, has a more intricate web of relationships and would experience a more significant disruption if they quit. Job embeddedness has shown to be a stronger predictor of retention, employee attendance and performance than the best well-known psychological constructs such as job satisfaction or organisational commitment (Holtom, Mitchell, & Lee, 2006). For an overview of the theoretical constructs, see Figure 1.

<table>
<thead>
<tr>
<th>Constructs</th>
<th>Relationship Between Constructs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Personal</strong></td>
<td><strong>Social Cognitive Theory</strong></td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>Behavioral</td>
</tr>
<tr>
<td>Outcome expectancies</td>
<td>Environmental</td>
</tr>
<tr>
<td>Self-Regulation</td>
<td>Reciprocal</td>
</tr>
<tr>
<td>Locus of Control</td>
<td>Determinism</td>
</tr>
<tr>
<td>Environmental</td>
<td>Physical</td>
</tr>
<tr>
<td><strong>Environmental</strong></td>
<td>Personal</td>
</tr>
</tbody>
</table>
Approach and aim of this study

Data relying entirely on quantitative research provide limited information due to the restricted content of questionnaires and consequently possibly overlook essential aspects. Therefore, qualitative research can be complimentary as it goes beyond what is provided by quantitative measures by giving insight into the reality and multifaceted experiences.
of individuals, by telling us in their own words their perspectives and what it means to
them (Forrester, 2010; Learmonth & Motl, 2016). Suggestions have been made for health
professionals to listen to the needs, desires and capabilities of the MS population to ensure
lasting adherence to physical exercise (Learmonth et al., 2017). Therefore, studies that
incorporate people with MS perspectives are of utmost importance as part of the research
that may inform health policies as well as the design and development of clinical health
interventions for them. This shift to include consumer participation is recognised today
worldwide as a central element of health policy, where consumers and their organisations
have a right to be involved in choices and decisions regarding their care. If a health
intervention is deficient due to the lack of consumer input, it greatly reduces the chance
of success of the programme (Australian Government, 2016; Staniszewska, 2009).

Emerging evidence is beginning to provide a clear picture of exercise behaviours in
persons with MS. Although numerous studies have been conducted on exercise in relation
to MS, no known research examined factors that predict retention in exercise activity for
persons with MS. As non-adherence and drop-outs of these programmes are high and
hinder the benefits of exercise as previously outlined, it is valuable to enhance our
understanding of what keeps persons with MS engaged in exercise programmes overtime,
and especially what specific factors facilitate retention. Ultimately the goal of this
research is to improve health and quality of life for people with MS by providing the
support they need to maximise the benefits of physical activity and to adopt it as their
life-long habit. Some key questions are how to support persons with MS to maintain their
exercise activity? And what do service providers need to address in order to retain a high
number of participants in their exercise programmes? Therefore instead of asking why do
people drop out, the question was reversed to why do people stay in exercise
programmes? On this basis, the study aimed to examine the research question “What are
the psychosocial factors that predict participation and retention in exercise activity and support programmes for people with Multiple Sclerosis?"

**Method**

**Participants**

Participants were recruited through the Multiple Sclerosis society of Western Australia (MSWA, 2017). Fifteen participants (twelve women and three men) were included in the study by meeting the criteria of being above 18 years of age and having an MS diagnosis, with an age range of 42 to 73 years (M =54.8 years, SD = 8.46). Fourteen participants identified as white and one person as white/aboriginal. The time since their diagnosis with MS ranged from 1 to 41 years (M= 14.4 years, SD=10.86). All unemployed participants within working age were unable to work due to their disability. Ethical approval was acquired from Murdoch University Human Ethics Committee (Appendix A), and each participant completed an informed consent procedure (Appendix B). Demographic characteristics, indicators of MS and exercise are presented in Table 1.
<table>
<thead>
<tr>
<th>Participant No.</th>
<th>Gender</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Married or in partnership</th>
<th>Level of Education</th>
<th>Employment</th>
<th>Years since diagnosed</th>
<th>Mobility Device</th>
<th>Type of MS</th>
<th>Exercise Frequency</th>
<th>Exercise Facility</th>
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<tbody>
<tr>
<td>1</td>
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<td>WH, SC</td>
<td>PP</td>
<td>Low</td>
<td>MSWA</td>
</tr>
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<td>Unemployed</td>
<td>29</td>
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<td>SP</td>
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<td>MSWA</td>
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<td>Part-Time</td>
<td>22</td>
<td>WH, SC</td>
<td>SP</td>
<td>Low</td>
<td>MSWA</td>
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<td>MSWA</td>
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<td>CA, WH, SC</td>
<td>RR</td>
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<td>Other</td>
</tr>
<tr>
<td>6</td>
<td>M</td>
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<td>25</td>
<td>WH, SC</td>
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<td>MSWA &amp; Other</td>
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<td>RR</td>
<td>Low</td>
<td>MSWA</td>
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<tr>
<td>8</td>
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<td>Unemployed</td>
<td>17</td>
<td>WH, SC</td>
<td>SP</td>
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<td>MSWA &amp; Other</td>
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<tr>
<td>9</td>
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<td>Part-Time</td>
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<td>No</td>
<td>RR</td>
<td>Moderate</td>
<td>MSWA &amp; Other</td>
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<td>MSWA &amp; Other</td>
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<td>Bachelor degree or above</td>
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<td>MSWA</td>
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<td>Unemployed</td>
<td>3</td>
<td>CA</td>
<td>PP</td>
<td>Moderate</td>
<td>MSWA</td>
</tr>
</tbody>
</table>

Note: F, Female; M, Male; WH, Wheelchair; WA, Walker; SC, Scooter; CA, Cane; RR, relapsing-remitting; PP, primary-progressive; SP, secondary-progressive.
Exercise frequency in times per week: Low (0-2); Moderate (3-4); High (5 or more). MSWA, Multiple Sclerosis Society of Western Australia.
Materials

The level of disability in motor and ambulatory dysfunction was measured with the Patient Determined Disease Steps (PDDS) scale (Appendix C), (Hadjimichael et al., 2007). It is a self-report measure using an ordinal scale of nine levels of disability ranging from normal (0) to being bedridden (8). Scores from the PDDS scale are strongly correlated ($r = 0.78$, Learmonth, Motl, Sandroff, Pula, & Cadavid, 2013) to the physician administered Expanded Disability Status Scale (EDSS; Kurtzke, 1983).

Procedure and Data collection

Recruitment was made through the MSWA in Perth and included posters (Appendix D), newsletter advertisements and word-of-mouth from MSWA physiotherapists. Interested participants were later phoned and given further information as well as being screened for inclusion criteria (Appendix E). Those who met the inclusion criteria were scheduled for an interview either in person at the MSWA facility (seven participants) or over the phone (eight participants). One participant was excluded due to not being available within the study timeframe. All participants took part in a semi-structured interview lasting between 25-60 minutes. They were asked about their experiences with physical exercise activity as a person with MS. Semi-structured interview were chosen for its flexible approach where the conversation can change direction, as new issues may arise that were not initially included in the questions (Gibson, & Hugh-Jones, 2012). The interview started by letting the participants read the information letter (Appendix F) and sign the consent form. Participants scheduled for a phone interview had to sign and return the consent form beforehand. After that, the demographic information was collected, and the PDDS-scale administered. The interview schedule (Appendix G) designed explicitly for this study focused on psychosocial factors that are implicated in attending exercise programmes such as the role of social factors, self-efficacy and autonomy, expectations and behavioural attitudes. The interview started with general questions such as “What
factors are helpful to you in attending exercise programmes here at MSWA?” These were later followed up with probes based on the theoretical frameworks, to elicit more specific responses, such as “How do the social aspects of the exercise programmes encourage you to stick with it?” The order of questions and wording varied slightly in the interviews as to assist the flow of each conversation (Forrester, 2010). Two weeks later participants were sent a summary of the key themes of the interview for member checking (Lincoln & Guba, 1985) where they were asked to confirm the accuracy of the report. The summary provided an opportunity for the participants to comment further.

**Analytic Approach**

Data was analysed using inductive thematic analysis in accordance with Braun and Clarke (2006). This study is a pilot study and explorative in its nature, and on this basis, the identified themes were data driven, rather than informed by the theoretical framework. However, more of a deductive approach was used in designing part of the interview questions with the aim to elicit specific information in relation to the theories as well as in the final stage of analysis. Furthermore, the analysis was underpinned by a critical realist epistemology that recognises the ways individuals ascribe meaning to their experiences through language as well as it acknowledges the socially constructed ways in which we understand reality (Lyons & Coyle, 2016). Critical realism was chosen as it allows the analysis to be grounded in the experiences of the participants while still allowing for a critical contextual analysis informed by the selected theoretical framework.

Both latent and semantic meanings have been employed to describe the results and the researcher interacted with the data through an active and constructive process (Braun & Clarke, 2006). The inductive analysis consisted of six steps. First, there was familiarisation with the transcripts (Appendix H) while taking notes of initial impressions. Second, key patterns of meaning were identified by coding while comparing the interviews and looking for similarities and differences (see examples of analysis in
Appendix I). Third, codes were translated into themes while ideas were considered a theme when expressed by three or more participants (Clarke, & Braun, 2015). The fourth step involved reviewing potential themes. The fifth step consisted of defining themes, subthemes and their relationships. This stage of analysis was semantic due to being based on the surface meanings of the words that participants used describing their reality. The sixth step consisted of selecting data extracts for the themes and writing up the report by weaving together the excerpts and analytical notes as a coherent narrative. At this final stage, the themes were linked back to the theoretical frameworks that provided a lens through which the data was interpreted (deductive analysis). Latent meanings were included as well at this point.

Pseudonyms have been used to ensure confidentiality, display gender as well as how the quotes were obtained from a variety of participants. Within the quotes, some clarifications are written in square brackets, and an ellipsis indicates a short pause or a short edit.

**Analysis & Discussion**

This study aimed to examine the psychosocial factors that predict participation and retention in exercise activity and support programmes for people with MS. In accordance with SCT, this analysis identified both personal and environmental factors that were separated into three main themes. Personal factors were divided into two themes, “attitudes about purpose” (cognitive aspects) and “improved well-being” (functioning aspects), while environmental factors remained as one theme, “connection and support” (social aspects). Within these themes, there was a complexity of interconnected subthemes at play.

**Personal factors**

*Theme 1: Attitudes about purpose (cognitive aspects)*
Two-thirds of participants spoke of purpose and stressed how the “mindset” was an important aspect of their motivations to exercise. Further, thinking about the purpose of why they were exercising seemed to motivate exercise behaviour. Reasons identified were managing MS, maintaining functions and independence, the hope of improvement and being a positive influence on others. Further thoughts about being determined and committed to this purpose enhanced motivation. The three subthemes that were found within this theme were “managing MS”, “determination” and “in relation to others”.

**Managing MS** Over half of the participants were motivated to engage in exercise due to the belief that it was an essential part of managing their disease, by either maintaining current functions, regain previous capacities or to prevent further deterioration due to MS.

> I believe it’s all about maintaining… maintenance is really, really important. Because it is progressive, you don’t have any drugs… most of the drugs sound horrendous anyway. I think primarily…I have to slow the progression and to improve… the only thing is exercise. (Elizabeth)

Elizabeth expressed how she used exercise to maintain her current functions and prevent further deterioration. She further mentioned that exercise was one of the main options available for her as an intervention in the progression of MS as other available options such as drugs was not attractive to her. Exercise offers persons with MS some perceived control over the disease by giving them a choice of something they can do to cause a difference in their situation. For others, exercise offers “hope” that their condition may improve.

> I want to improve my mobility… I’m very obese, and so I’m hoping that some more exercise… will help with some weight loss… I lost a lot of my sort of balance and sort of sensation in my feet. So I don’t want it to get worse, …so when I think about that… that helps me get changed and get out the door. (Isabel)

For Isabel, it was not so much about maintenance as the goal of improvement.
Majority of participants with walking mobility expressed how their fear of relapse or worsening of symptoms with a possibility of ending up in a wheelchair was motivating them to keep moving as a way to remain independent. One-third of the participants spoke of fear as a motivation to exercise. These are examples of outcome expectancies influencing motives, and as these two examples above demonstrate both positive and negative outcomes can affect motivations to exercise. (SCT; Bandura, 1989a, 1989b). Further, when participants were thinking about exercise as a way to remain independent, their exercise motivation was enhanced.

You gotta keep moving. I don’t want to if I don’t have to… end up in a wheelchair. I don’t wanna be dependent on somebody else to care for me. I want to be independent and by keeping mobility and flexibility remain independent. (Isabel)

As many participants had experienced becoming more dependent on others due to their MS, maintaining their current independence was shown important. The thoughts of independence reveal an underlying psychological need for autonomy and some perceived control in a challenging situation. While many things are beyond their control, participants were motivated in taking control wherever it was possible. One way they could do this was to use exercise as a way to manage their disease based upon their capabilities, rather than be controlled by their outer circumstances. This finding is supported by Newitt et al. (2016) who found maintaining independence to be one of the most common motivators for exercise participation in this population.

Exercise for persons with MS was not necessarily connected to noticeable improvements.

I often think I don’t know if this is helping at all. But I have to believe it is. Does that make sense? It’s not like I notice it… but um I have to sort of believe that it is, that I’m achieving my goal… I guess I convinced myself that it’s of benefit to me. (Kylie)

This quote demonstrates how the belief in itself is a strong motivation, independent of the physical evidence supporting it.
**Determination** The determination to exercise was shown to be an essential factor in motivating exercise. Even though all participants expressed commitment to exercise, there was observed a variability of self-efficacy in translating that motivation into action. It was found that high exercisers expressed a different combination of motivational factors to low exercisers. For example, high exercisers demonstrated motives such as benefits from the previous exercise along with high self-determination, self-efficacy and more of intrinsic motivations, where low exercisers showed mainly attitudinal motivations such as beliefs that it was beneficial or hope that things will improve, along with low self-efficacy, self-determination and extrinsic motivations as more common. Further high exercisers demonstrated more self-efficacy and confidence in their ability to manage MS compared to low exercisers. The following quote represents a high exerciser.

It get’s back to my… mindset to do it, but once it sunk in I never stop and it’s a religious thing I do… I’m a stubborn person, so I’m determined to do it… it taken me some time to get there… It’s just you need to commit to doing it. (Molly, exercise daily)

Molly exhibits high self-determination, intrinsic motivation and a commitment to her exercise regime. In contrast, other participants struggle to keep their motivation up despite their good intentions, indicative of low self-determination and self-efficacy. These persons need support from others (extrinsic motivation) to help them get motivated. The following quote is an example from a low exerciser.

I’m not always well motivated… I’ve got a friend staying with me. And… she motivates me a bit more because she says come on let’s go. And… it’s just getting over the hurdle of… getting ready and actually going out cause I find that sort of tiring, as well, um, so it’s good having somebody else, that helps motivate me a little bit more. (Isabel, exercise 0-2 times per week)

As Isabel expresses “the hurdles and tiring activity of getting ready” is reducing her determination. This quote demonstrates how the barriers persons with MS are faced with are mediating factors between their motivation and exercise behaviour. As discussed
above these barriers are often specific to persons with MS (e.g. physical impairment, pain, lack of mobility), (Asano et al. 2013), and many participants spoke of how they often had to push themselves to exercise when facing such barriers. The following woman is pushing herself against her fatigue and physical impairments.

I push myself… I have to push myself to get up, get out of bed, do what I have to do…when I’m there at the physio… cause I know its only once a week that I get to go out and stretch my body… so I tend to push myself just a little bit further… but I know that I will feel better for it, and it’s helping me. (Emily)

This quote demonstrates how they use their purpose and strength of determination to overcome these barriers. The knowing that it will help them and that they will feel better for it (positive outcome expectations, SCT, TPB) is the purpose that feeds that determination.

Four participants experienced setbacks after pushing themselves too much, indicating a difficulty to find the right balance between the determination to exercise and the right amount of exercise.

For me, it is important to not overdo it. So when I do it… a normal person have some exercise, and they recover fairly fast, but with MS, or I don’t do that, so if I take it too far, and I like to push myself… I could not be able to be very effective with my body for a couple of days maybe. (Jason)

Jason demonstrates that persons with a disability are different from the general population in the amount of exercise they can endure. More is not always better, but rather less can sometimes be more beneficial. For each person with a disability, there is possibly a specific amount of exercise beyond which an additional increase is not beneficial anymore, and possibly even harmful. These results are in support of the previous findings of the “critical edge” by Smith et al. (2009). The participant’s level of perceived control (TPB) appears to be the mediating factor in recognising that edge and find this balance.
Further to have the determination to make good health behaviour choices are a demonstration of self-efficacy (SCT) as well as competency (SDT) as the quote below illustrates. Two women, who exhibited high self-determination in relation to exercise, spoke of how it had taken them years to develop that determination.

The level of activity ten years ago was nothing like what I’m doing now… It took a few years to sink into the brain that you actually need to do it… and that’s why I do my exercises every morning religiously. (Molly)

Both these women started their exercise due to extrinsic (external) motivations. For example, one woman was encouraged to exercise by her friends while the other started out of fear due to a scare she had previously experienced when falling and not having the strength to get up by herself. With their exercise being positively reinforced overtime, encouraging continued exercise, the quality of their motivation developed more towards an internalised form of motivation (intrinsic motivation) that was driven by a sense of choice and volition (Deci & Ryan, 2008b). Their accounts suggest that intrinsic motivation is built up over time in relation to self-efficacy, self-determination and positive reinforcement from the previous exercise. All the participants engaged in exercise by their own initiative, signifying autonomous self-determination that has been shown to predict adherence and persistence and is required for effective performance while also being correlated with psychological health (Ryan, & Deci, 2008a, 2008b).

In relation to others Majority of participants had the perception that other MS-participants held similar views as themselves in regards to exercise, which is an example of subjective norms as postulated in TPB.

I think I’m not in…that boat by myself. I think that other people feel the same way, they don’t really do the exercise that perhaps they should (Laughter). (Daisy)

For some participants the motivation to exercise was enhanced by thinking of significant others, often children, whom they perceived wanted them to exercise. Further, Jessica spoke of how thinking about her family positively influenced her to exercise and also
how exercise was used to reassure her family that “mum is okay” and participates in life like other “normal” people, despite her disability”.

I’m trying to help myself and… I try to keep my life as normal as possible… I don’t like it when my family sees that I’m struggling. So it’s sort of like… if they can see that I’m still exercising they sort of go ah yeah… mums still doing alright like if I wasn’t exercising they’d know that something is really wrong (laughter)… I think they would want me to be as healthy as I can be… if I’m trying to help myself as much as possible, I’d like to be a positive influence on them as well. (Jessica)

This quote illustrates how the belief of whether one thinks one’s social network want one to perform a specific behaviour influences ones motivation, as suggested by the injunctive subjective norms construct in TPB (Ajzen, 1991). It was found that family members had the most normative influence on exercise. Others spoke of the goal of keeping up what they perceived to be a “normal” life.

Our goal is to feel more fit, and more strength, and have more ability to have a normal life whatever that is. I’m not sure I know what a normal life is anymore. But just to… be able to do the things that you would like. (Jason)

This idea of being normal is linked to a belief of what normal is, something we then can compare ourselves to and assess how close or distant we are to it. This attempt to be normal enhanced motivations to exercise as well, as exercise itself was seen a sign of normality. “Feeling normal” was previously found as a motivation to exercise for persons with neuromusculoskeletal diseases, such as MS by Newitt, Barnett and Crowe (2016).

Another participant talked about how she was encouraged by seeing how other people with MS, even worse than herself, dealt with their disability and kept going despite being angry or scared, feelings she believed they all shared.

Thursday morning at physio like its good to see that some of them who are definitely… are more advanced than me, that they’re still trying to help themselves and that’s a really good positive thing that I get out of it… I mean we all get down, and we all get um you know
angry… um and scared and that sort of thing but… you know it’s good to see that other people do try to keep going. (Jessica)

This quote is an example of descriptive norms (TPB; Ajzen, 1991) that suggests that if one knows that others in their social network perform a specific behaviour, it is known to influence one in carrying out the same behaviour as well.

**Theme 2: Improved wellbeing (functioning aspects)**

Improvements in their general wellbeing and daily functioning were reported to enhance motivation to exercise for many participants. The exercise was found to improve physical strength, abilities, symptoms as well as generating positive feelings of wellness, confidence and accomplishment. The three subthemes that were found within this theme were “physical improvements”, “psychological improvements” and “improvements in daily functioning”.

**Physical improvements** The participant’s reported a considerable variation in the benefits they received from their exercise. A few observed major progress in the reduction of symptoms and increased abilities while others noticed none to moderate gains. The degrees of recovery were positively related to their level of exercise. Some physical improvements identified were in the area of muscle strength, flexibility, mobility, balance, sleep, bladder function and energy with less pain and numbness in various parts of the body. These improvements are similar to what has previously been reported in the literature (Ensari et al., 2014; Latimer-Cheung et al., 2013; Motl, 2014; Motl & Gosney, 2008; Pilutti et al., 2013; Snook & Motl, 2009).

When I start going more regularly, there’s definitely been improvement in sort of my flexibility… my mobility is definitely better now than what it was say five years ago…I’d sleep better at night. (Isabel)

Furthermore, one-third of the participants expressed that the benefits from their previous exercise were motivating them to continue.
With the strength work I noticed that my body is balanced, my body’s shape changed. Um, which made, which pushed me to keep doing it. (Charlotte)

In addition, five participants spoke of how they felt worse if not exercising.

I always felt that when I don’t exercise my body feels much worse…more pain, more symptoms um… yeah, just I feel more fatigue if I don’t do it… so I always feel that I need to do exercise. (Natalie)

Both Charlotte’s and Natalie’s accounts illustrate how exercise can be a motivating factor to further exercise through both positive (e.g., feeling better from exercising) and negative (e.g., feeling worse if not exercising) reinforcement as suggested by SCT.

**Psychological improvements** Although the majority of benefits discussed were on the physical level, eight participants expressed how exercise generated positive feelings of wellness and counteracted depression, and one participant reported the benefit of clearer thinking. Two persons further mentioned that exercise assisted them in coping with their disability.

I sit [in a wheelchair] most of the time and just to get up and move… it just keeps me more positive you know, about dealing with my disability… you get depressed about what you can do and what you cant do. (Emily)

It was further spoken of how the act of doing something in the interest of their wellbeing generated positive feelings in itself. It gave a sense of satisfaction, purpose and accomplishment, as was mentioned by eight participants. These positive psychological feelings reinforced further exercise (SCT).

I think the wellness, the feeling of wellness, a feeling of achievement… it is a feeling of accomplishing something. Um, there’s purpose, um… when you do a good days work you feel good, you go home and you’re tired… it’s like I’ve had a good days work you know. (Thomas)

These positive feelings of wellness and achievement due to one’s actions satisfy the deeper psychological need for **competence** as suggested by Deci & Ryan (SDT, 2000).
Furthermore, it was found that participant’s confidence was enhanced by exercise through improvements in strength and abilities, satisfying the need for competence as well. It was only high-exercisers with major improvements that reported increased confidence in this study and Charlotte was one of them.

I’m far more confident than I ever been… I didn’t think I was able to do anything cause I felt weak. So that was a great thing, that [exercise] was something that built my confidence, and I realised that the strength work that I’ve been doing has now given me hope that I can do other things. (Charlotte)

The confidence was found to increase the participants daily functioning, social participation as well as their perceived behavioural control (TPB, Ajzen, 1991).

**Improved daily functioning** Improvements were identified in the areas of regaining previously lost abilities as seen in their daily activities (e.g. dressing, brushing teeth, cooking, shopping, using public transport, travel overseas, increased ability to work). As one participant explained, these small little changes are huge for the individual.

For me to go to exercise, it means to me that… I can work every day and work longer hours than I ever done before… I can do my shopping, cooking and cleaning… I don’t need any help. I noticed little things… like putting my underwear on, or I was able to balance… I notice I lift my feet better, where I used to drag and… since I’ve done strength work that’s hugely changed… it made such a difference to my daily activity… they are little small changes, but they are big changes for me. (Charlotte)

But exercise could also interfere with the day-to-day functioning as Jason spoke of.

If I do a lot of exercise, I could do that, but that could also mean like I couldn’t go shopping afterwards for a couple of hours because I need to recover. (Jason)

Exercise at MSWA was further shown to motivate four participants to exercise at home, a fact that has not been found reported in previous literature. As Kylie, a woman in a wheelchair spoke of.

I think that because I come to exercise and I do these exercises I, I’m reminded when I’m at home during the week to do little things like… in the mornings before I get out of bed I do a
couple of bed exercises… I wouldn’t do those things if I didn’t have the regular attendance here [at MSWA] where I kind of get checked up on, and I can brag a bit and say yeah I do these things. Its motivation I suppose to do it at home. (Kylie)

As was demonstrated in theme 2, if the participants would stop their exercise activity, they would experience increase in symptoms as well as decrease in psychological wellbeing, functions and abilities affecting their daily life and work opportunities. These losses would influence their decision of whether to leave or stay in exercise activity, as suggested by the construct sacrifice in JET. These improvements in symptoms and functioning were found to reinforce further exercise activity (SCT).

**Environmental factors**

**Theme 3: Connection and Support (social aspects)**

The social aspects of exercise were mentioned as being important and enhanced motivation to exercise for most participants. Exercise provided an opportunity to get out of the house and being part of life, connecting with others, meeting new friends and receive support. For some exercise filled the social function that their work had previously provided in their life. The three subthemes identified were “connection versus isolation”, “new friends who understand” and “finding support”.

**Connection versus isolation** Living with MS can be challenging and often limit the social interactions in their daily life as well as the opportunities to get out and participate socially, something that work usually provides. But exercise was found to offer circumstances that counteracted this isolation and satisfy the psychological need for relatedness (SDT, Ryan & Deci, 2008a, 2008b), as Emily recounted.

I think that exercise is also linked to the fact that I have to physically get out of the house. I get out, and I meet people, so it’s a social thing as well, as well as the exercise. I was pretty much; you know just stayed at home. No, I’m not going there I’m not doing that. Now I got people there who will support me and will help me with things, and now I’m quite happy to
go. I know I shouldn’t just sit around and do nothing, I need to get out and do things and being a part of life. (Emily)

Some participants specifically talked about how exercise had replaced the social function their work previously had.

There’s a social aspect of it [the exercise] too. I’m getting out, I’m not sitting around so, and that’s an important thing for me… When I used to work… I used to form connections or relationships because of my work, people would come to me and relate to me through my job. But now people see me in my wheelchair or on my scooter, and I go out… this is how I meet people. (Thomas)

Three of the participants spoke of being isolated as part of having MS.

I don’t have a big social, like a big network. Um, so I possibly would be considered socially isolated because I moved… from where I was living where most my friends were (Isabel)

As has been shown exercise provides an opportunity to connect with others, participate in life and reduce isolation for people with MS, factors that enhance motivations.

**New friends who understand** One-third of the participants spoke of how exercise gave a chance of meeting new friends who can understand what they are going through, without needing to provide any explanations.

I met up with a great group of people through the MS society… we all know what we are dealing with… so yeah, we got that connection… so yeah we understand and don’t need to go into big explanations as to other people. We just know. (Emily)

A few participants also shared how they would never mix with non-MS persons for their exercise. In MS-specific exercise groups, they could relax and relate to others based on shared experiences in a judgment-free environment, in contrast to a regular gym where they could be judged or laughed at because they can’t do everything as others do.

I go every week to the MS because they have a service there that really helps and you can also meet up with other people with MS… a normal class of anything, is something that would freak me out because you’re just not like everybody else anymore (laugh). (Elizabeth)
The interviews reveal the importance of connections (links) that exercise provides for them. In contrast, for a few participants, the social interactions were not important at all, and one person even preferred non-MS-specific exercise. Further, the social interactions sometimes felt confronting due to not being in a social mood or by seeing others with MS. Others just did not have the need for social interactions as they had that satisfied from other sources in their life.

It’s also social as well, but I do struggle with that a bit… because sometimes I just don’t want to talk to anybody so I don’t… I find that hard, very confronting… Yeah, just because I get my social thing from my work and from my family and from my friends. (Jessica)

Jessica was not in favour of the social interactions around exercise although she was ok with MS-specific exercise, in contrast to Jason who spoke of how he was confronted by going to MS-specific exercise and what he perceived to be a “sick” environment.

When I’ve been going to rehab, everyone is sick… if I go to a place that doesn’t focus on MS that feels just better within me. Cause then… I don’t see myself as sick maybe. If I go to an MS place, I will be reminded that I have MS. (Jason)

For these individuals the social interaction was not a motivation to attend exercise activity, it was instead other factors that motivated them such as attitudes of purpose or improved wellbeing factors. These are examples of how the preferences and needs that drive exercise activity are individual, complex and varied. While MS-specific exercise is a good fit and increase embeddedness for Elizabeth, it is a bad fit and decreases embeddedness for Jason, and exercising elsewhere represents a better fit for him. So the same aspect (MS-specific exercise) can in fact either increase or lower embeddedness, depending on the fit with the preferences of the individual.

**Finding Support** To receive support for exercise participation was demonstrated to increase the motivation to exercise. This support was coming from both other participants and physiotherapists during exercise activity as well as from others outside of the exercise programme such as friends, family members and sometimes doctors. The professional
support from the physiotherapists was an essential part of the reported satisfaction with the programme at MSWA. The professional and targeted assistance based on knowledge of MS contributed to participants feeling very safe and looked after during exercise, as was mentioned by eight participants. Further, it was said that the week-to-week monitoring of their disease was important as most of the participants only met their neurologist once a year. It was observed that participants who exercised at MSWA reported higher satisfaction with their exercise support than participants who exercised outside of MSWA.

I can’t imagine anywhere else in the community I could get the targeted and the focused assistance I get here, understanding my condition, yeah. Um, well that monitoring I suppose of um my physical abilities… The physios are actually an important part of keeping track I suppose of my health, noticing things… No, I feel very looked after I suppose by the staff here. (Kylie)

This type of targeted intervention was experienced as very positive by the participants and have previously been demonstrated to be helpful to minimise any possible adverse experiences while exercising while encouraging the positive benefits of continued exercise (Motl et al., 2006; van der Ploeg et al., 2004). But unfortunately, sometimes the most well-intentioned support can have adverse effects like William experienced.

A few years ago when I first went to the MS society, I was told mate you’ll be alright, and then you are not alright… You can’t walk, and it is a big shock… but they lie to you by saying you are going to be alright… Yeah, there’s a lot of hardship in accepting and dealing with and being positive about what you can do, and… what you can’t do… you don’t need the additional burden. (William)

This quote illustrates how good intended support can be detrimental if it is not realistic, but instead used as an avoidance of facing the hardship these people deal with in their lives.
But it is not only professional assistance the physiotherapists provide. They also offer an opportunity for connection as Kylie spoke of.

I really enjoy the interaction with the physios and physio assistants for help. Yeah. I have plenty of conversation with them… I enjoy having conversations, and they ask questions about my life, and I chat to them about theirs. (Kylie)

The participants also mentioned how they support each other as well.

We [participants at MSWA] support each other, as much as we can, um, without taking someone else’s problems on your shoulders. (Daisy)

Encouragement and support from friends and family were enhancing motivations to exercise as well. Two-thirds of participants felt supported by their family and friends. For example, Molly shared how her husband supports her by making her exercise equipment to use at home.

He is very supportive… he is making me a wobble board and stuff like the equipment I use here [at MSWA]… I would be completely lost without him… I would struggle more if I didn’t have him. (Molly)

In summary, as has been demonstrated the social aspects play an essential role in both motivation to exercise and why persons with MS stay in exercise programmes. The social, interpersonal context was found to satisfy basic psychological needs of relatedness and competency. The need for connection is fundamental as a human being, and as has been shown many persons with MS often become more isolated due to their disability, thus exercise offers them an opportunity to connect with others and receive support in a challenging situation, and thereby satisfies part of these fundamental needs. Ryan and Deci (2000) argue that human needs are an important factor implicated in motivations and their potency. This construct provides an added dimension that influences motivations, besides plain goal-oriented motives that are a more common focus, and the results of this study are in strong support of this concept as these accounts provide evidence of these needs being implicated in motivations. Furthermore, these positive
social aspects have to be sacrificed if one chose to stop the exercise. For many, their exercise activity had become a vital part of their daily routine and lives, reflecting high embeddedness. Nine participants spoke of how they would miss it if they stopped. The following quote illustrates this well.

It’s the overall wellbeing which includes the exercises, physically moving, it’s the social aspect of the group, and yeah, it’s a whole package. I love going to exercise… Yeah, it’s a big part of my life at the moment… if they say we are closing the MS society down in Western Australia and you can no longer come down to the physio then yeah I’d be totally devastated. (Emily)

**General Discussion**

*Retention to exercise activity*

As has been established, many motivational factors are implicated in and helpful in predicting retention. The JET by Mitchell & Lee (2001) provides a different perspective than mere motivations in looking at retention through their construct of embeddedness. According to this approach, the combined forces of the exercise activity’s *fit* with their personal preferences, connections and supports (*links*) as well as benefits (e.g., improvements), are factors that participants would have to *sacrifice* if they chose to stop their exercise activity (Holtom, Mitchell & Lee, 2006). Furthermore, the perception of this loss would influence their decision to stay or leave. The more embedded or attached a person is with the environments, the more likely they are to stay according to the JET (Mitchell & Lee, 2001). So, in linking this all together, the participant’s who experience *improved wellbeing* and benefit from the *connections and support* the exercise programme provides, are more likely to stay, than those who experience less fulfillment in these areas. There are many complex individual characteristics as well as
environmental factors that are involved in determining the level of embeddedness, such as preferences, health condition, attitudes and expectations, social norms, level of perceived control, motivations, psychological needs and social support. This study found participants demonstrating aspects of both high and low embeddedness in relation to fit, links and sacrifice and their exercise activity (see table 2). JET and these findings are of interest as it can inform future clinical interventions to build on factors that increase embeddedness for participants, especially for those showing low on some embeddedness dimensions, as a way to improve retention in exercise activity (Holtom, Mitchell & Lee, 2006).
Table 2.

*High Embeddedness versus Low Embeddedness*

<table>
<thead>
<tr>
<th>Why People Stay</th>
<th>Fit (Comfort and compatibility with an Exercise programme)</th>
<th>Links (Connections to people and activities in the Exercise programme)</th>
<th>Sacrifice (What I have to give up by leaving the Exercise programme)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>High</strong></td>
<td>• Professional targeted, and focused exercise assistance, and monitoring for people with MS.</td>
<td>• The specialized knowledge, understanding and week-to-week support from the physiotherapists.</td>
<td>• Maintenance of and improvements in physical, psychological and daily functioning.</td>
</tr>
<tr>
<td></td>
<td>• Prefer MS-specific exercise, not comfortable exercising with others.</td>
<td>• New friends who understand.</td>
<td>• Enjoy exercise and it gives a sense of accomplishment, purpose and satisfaction.</td>
</tr>
<tr>
<td></td>
<td>• Happy with what MSWA offers.</td>
<td>• Friendliness and support of participants and staff.</td>
<td>• Free exercise classes at MSWA.</td>
</tr>
<tr>
<td></td>
<td>• Made exercise a part of my life and routine.</td>
<td>• Exercise at MSWA motivates one to do exercise at home.</td>
<td>• Enjoy exercise</td>
</tr>
<tr>
<td><strong>Low</strong></td>
<td>• Lack of a variety of exercise options.</td>
<td>• Not interested in talking to others about MS.</td>
<td>• Don’t enjoy exercise.</td>
</tr>
<tr>
<td></td>
<td>• Lack of supportive facilities and suitable times (in rural area).</td>
<td>• Prefer mixing with non-MS exercisers.</td>
<td>• Don’t feel any benefits and don’t know if it does anything for me.</td>
</tr>
<tr>
<td></td>
<td>• Exercise facility needs to be close-by.</td>
<td></td>
<td>• Can feel more pain or worse after exercise.</td>
</tr>
<tr>
<td></td>
<td>• “Sick environment” - I try to feel as normal as possible. I don’t want to be reminded I’ve got MS.</td>
<td></td>
<td>• Lack of confidence or feeling unsafe.</td>
</tr>
<tr>
<td></td>
<td>• Prefer non-MS specific exercise</td>
<td></td>
<td>• Don’t like the word exercise.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Hard to find the right balance of exercise and not overdo it.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Temperature changes while exercising can make symptoms worse.</td>
</tr>
</tbody>
</table>
Utility of Frameworks

In general, the SCT, TPB, SDT and JET were found useful in understanding exercise behaviour. The Combined constructs from the four theories allowed for a more comprehensive picture and understanding of the processes and factors influencing motivations and retention in exercise activity. A limitation found in these theories was that they do not explain how health condition relates to cognition, motivations, embeddedness or behaviour. The health condition is implicated in motivations and exercise behaviour for people with MS and is therefore of particular importance for this population. A descriptive path model was generated from integrating SCT, TPB, SDT and JET into one model. This model was done with the aim to provide a hypothetical model that identifies the combined motivations and interactions that can predict exercise behaviour and retention in exercise activity for persons with MS (see figure 2).
Figure 2. An integrated path model of factors that directly or indirectly influence exercise participation including Self-determination theory, Theory of planned behaviour, Social Cognitive theory and Job embeddedness theory.

In regards to Exercise with MS

**Personal**: including health condition

**Environmental**: including exercise facilities, organization, social support, professional support, transport, availability, financial support, lack of time.

**Behaviour**: Attending exercise

**Outcome**: Benefits of exercise (physical, psychological, social)
**Limitations and Future Research Directions**

This pilot study aimed to explore the experiences of participants, revealing themes in relation to their motivations towards exercise attendance. A limitation of this qualitative approach was the small sample size that limits the generalisations of these results. Furthermore, all the participants came through MSWA and were exercisers, a fact that excluded 78% of the MS population who according to previous findings do not exercise (Marrie et al., 2009; Motl et al., 2016). Self-selection through convenience sampling may have possibly biased these results by recruiting participants with high self-efficacy and autonomy, mainly women who are known to be more socially connected than men, or participants from 40 plus only.

Future research could incorporate quantitative measures for some of the constructs and themes in this study as well, for example, attitudes, social support, embeddedness, self-determination, autonomous motivation, self-efficacy and perceived control. This could help to evaluate how these constructs apply to a broader MS community in relation to exercise participation and adherence. Further, it would be beneficial to compare these themes and constructs between MS-exercisers and MS-non-exercisers. These results suggested a relationship between the level of self-determination and overcoming barriers to exercise, a point that is worthy of further investigation as it could reveal new strategies in which to help persons with MS to overcome barriers to exercise. Ideally, a future pilot intervention exercise study could be designed to assess some of these constructs through practical application in a real setting. For example, it could include teaching cognitive motivational strategies to improve the quality of motivations, such as strengthening self-determination, autonomy and intrinsic motivations (SDT, Ryan & Deci, 1985, 2000), and consequently the chances of overcoming barriers to exercise could increase. Further, it could target and develop strategies to increase individual embeddedness through purposefully build on factors that increase the fit, links and sacrifice, as well as many of
The motivational factors that were found in this study. These strategies could be highly beneficial to increase participation and adherence to exercise activity for the already active, but also especially helpful for MS non-exercisers who may need that extrinsic motivation to get started to move into a more active stage of health behaviour change for their wellbeing.

On this basis, individual assessments and targeted assistance may be beneficial based on the integrated path model (e.g. including needs assessments and quality of motivations in relation to personal barriers) as a way of identifying areas of limitations and assist in developing individually tailored support for long-term exercise participation and adherence.

Conclusion

This study aimed to examine the psychosocial factors that predict participation and retention in exercise activity and support programmes for people with MS. This study identified three themes, attitudes about purpose, improved wellbeing and an opportunity for connection and support that were found to influence motivations to exercise as well as enhancing participation in exercise activity. As has been demonstrated, a wide variety of complex inter-connected factors influence motivations to exercise for people with MS and can act as either a barrier or facilitator to participate, all depending on the individual preferences, beliefs and attitudes in interactions with their health condition and the environmental context. Furthermore, combining constructs from SCT, TPB, SDT and JET were found useful as it allowed for a more comprehensive picture of the underlying processes influencing motivations and retention in exercise activity. These findings contribute to the growing literature in the understanding of these influences on motivation and retention for people with MS and were in support of previous research (Christensen et al., 2016; Learmonth & Motl, 2016; Newitt et al., 2015). However, it further extended these results by bringing in new perspectives in regards to some aspects of motivations
as well as retention to exercise activity. These findings are valuable, as it will assist to inform future clinical interventions of factors implicated in retention and what they need to address in order to retain a high number of participants in exercise programmes. This further will help to improve quality of life for persons with MS. Although many strategies exist that improve exercise behaviour in persons with MS, this study endorse cognitive motivational strategies as well as building on the relational and supportive social aspects of exercise.
References


Appendix A
Ethics Approval Letter

Tuesday, 16 May 2017

Dr Yvonne Learmonth
School of Psychology and Exercise Science
Murdoch University

Dear Yvonne,

Project No. 2017/081
Project Title Retention to exercise-based support programmes in persons with multiple sclerosis

Your application in support of the above project was reviewed by the Murdoch University Human Research Ethics Psychology and Exercise Science Sub-Committee, and was:

APPROVED

Approval is granted on the understanding that research will be conducted according the standards of the National Statement on Ethical Conduct in Human Research (2007), the Australian Code for the Responsible Conduct of Research (2007) and Murdoch University policies at all times. You must also abide by the Human Research Ethics Committee’s standard conditions of approval (see attached). All reporting forms are available on the Research Ethics and Integrity web-site.

I wish you every success for your research.

Please quote your ethics project number in all correspondence.

Kind Regards,

Dr. Erich von Dietze
Manager
Research Ethics and Integrity

cc: Dr Brody Heritage, Mohini Sacha
Consent Form

Exercise and support program retention in people with Multiple Sclerosis.

I have read the participant information sheet, which explains the nature of the research and the possible risks. The information has been explained to me and all my questions have been satisfactorily answered. I have been given a copy of the information sheet to keep.

I am happy to be interviewed and for the interview to be audio recorded as part of this research. I understand that I do not have to answer particular questions if I do not want to and that I can withdraw at any time without needing to give a reason and without consequences to myself.

I agree that research data from the results of the study may be published provided my name or any identifying data is not used in the current as well as future studies. I have also been informed that I may not receive any direct benefits from participating in this study.

I understand that all information provided by me is treated as confidential and will not be released by the researcher to a third party unless required to do so by law.

Participant’s name:  ________________________

Signature of Participant:  ________________________ Date:  ....../..../.......

I confirm that I have provided the Information Letter concerning this study to the above participant; I have explained the study and have answered all questions asked of me.

Signature of researcher:  ________________________ Date:  ....../..../.......
Appendix C
PDDS-Scale

PDDS Patient-Determined Disease Steps

Please read the choices listed below and choose the one that best describes your own situation. This scale focuses mainly on how well you walk. Not everyone will find a description that reflects their condition exactly, but please mark the one category that describes your situation the closest.

☐ 0  Normal: I may have some mild symptoms, mostly sensory due to MS but they do not limit my activity. If I do have an attack, I return to normal when the attack has passed.

☐ 1  Mild Disability: I have some noticeable symptoms from my MS but they are minor and have only a small effect on my lifestyle.

☐ 2  Moderate Disability: I don't have any limitations in my walking ability. However, I do have significant problems due to MS that limit daily activities in other ways.

☐ 3  Gait Disability: MS does interfere with my activities, especially my walking. I can work a full day, but athletic or physically demanding activities are more difficult than they used to be. I usually don't need a cane or other assistance to walk, but I might need some assistance during an attack.

☐ 4  Early Cane: I use a cane or a single crutch or some other form of support (such as touching a wall or leaning on someone's arm) for walking all the time or part of the time, especially when walking outside. I think I can walk 25 feet in 20 seconds without a cane or crutch. I always need some assistance (cane or crutch) if I want to walk as far as 3 blocks.

☐ 5  Late Cane: To be able to walk 25 feet, I have to have a cane, crutch or someone to hold onto. I can get around the house or other buildings by holding onto furniture or touching the walls for support. I may use a scooter or wheelchair if I want to go greater distances.

☐ 6  Bilateral Support: To be able to walk as far as 25 feet I must have 2 canes or crutches or a walker. I may use a scooter or wheelchair for longer distances.

☐ 7  Wheelchair / Scooter: My main form of mobility is a wheelchair. I may be able to stand and/or take one or two steps, but I can't walk 25 feet, even with crutches or a walker.

☐ 8  Bedridden: Unable to sit in a wheelchair for more than one hour.
Appendix E

Screening Script

Study Introduction

During this study you will:

- Complete a brief questionnaire to tell us details about yourself
- Participate in an interview with a researcher and answer questions about what is helpful for a person with MS to be able to exercise regularly.
- Receive a printed copy of the interview for a possibility to provide feedback and further comments.

At the end you will receive a summary of the study findings.

Why Not Exercise?

Are you part of the MS community and interested in sharing your views about attendance in exercise support programs?

We are looking for people with MS over 18 who would like to be part of an interview study.

We are interested in hearing your views about what factors support your attendance in exercise programs and help you stay engaged over-time. This will require a 30-60 min interview session led by a researcher from Murdoch University.

During this study you will:

If you are interested, please contact:

Mohini Sacha (student researcher)
- : mohinidevi@hotmail.com
- : 0402 400 046

Dr Yvonne Learmonth (supervisor)
- : Y.Learmonth@murdoch.edu.au
- : 08 9360 6373
- : Social Sciences Building 440

Dr Brody Heritage (supervisor)
- : B.Heritage@murdoch.edu.au
- : 08 9360 6547
- : Social Sciences Building 440
Thank you for contacting us to register your interest in to find out more about our research study.
I am calling you to provide more information about our research study.
My name is Mohini Sacha, and I am a student researcher at Murdoch University here in Perth. I am currently completing my final honours thesis in Psychology. The purpose of our research study, Retention to exercise based support programmes in persons with Multiple Sclerosis, is looking at Why people with Multiple Sclerosis exercise, or choose not to exercise. We want to find out what variables help people with multiple sclerosis stay engaged in Exercise programmes.

We will be asking participants to fill in one short questionnaire about their disability status as well as participate in a 45-minute interview about their experiences and perspectives on exercise for people with Multiple Sclerosis.

Do you have any questions or concerns? Now that you have a basic understanding of the study, do you think you might be interested in participating?

**Caller is Interested**

But before enrolling people in this study, we need to determine if you may be eligible to participate. I would now like to ask you two questions.

1) Are you above 18 years of age?
2) Have you been diagnosed with Multiple Sclerosis?

I will keep all the information I receive from you by phone, including your name and any other identifying information confidential. Remember, your participation is voluntary, and you can withdraw your participation in this study at any time.

**Post Response Communication**

Ok, you are eligible to participate in this study.
Would you like to schedule an interview with me for the study? This can be done either at MSWA at 29 Parkhill way in Wilson 6107 or if you prefer via phone or skype.
Would you like me to email you out some information about the study before we meet?

Would it be possible to give me your phone nr/email address so I can contact you and send out information?

**Study Team Contact Information**

Thank you for taking the time to talk with me today. If you have any questions or concerns, please feel free to contact me. My name is Mohini Sacha, and I can be reached at 0402-400046 or mohinidevi@hotmail.com

Appendix F
Information Letter

**Exercise and Support Program Retention**

**In People with Multiple Sclerosis**
Participant Information

Dear Member of MSWA

We invite you to participate in a research study looking at the factors involved in retention in exercise and support programs for people with Multiple Sclerosis. This study is part of my Honours Degree in Psychology, supervised by Dr Yvonne Learmonth and Dr Brody Heritage at Murdoch University.

Nature and Purpose of the Study

There is a growing body of evidence confirming the benefits of physical activity and exercise in people with MS. Exercise programs have demonstrated improvements in aerobic capacity, balance, depression, fatigue, muscular strength, quality of life, and walking mobility. Exercise training has been considered the single most effective non-pharmacological type of symptomatic treatment in MS and represents a part of many MS rehabilitation programs.

Despite the known benefits of physical activity for people with MS, engagement in physical activity is particularly low compared to the general population and other chronic illness groups. Furthermore, studies investigating the effect of physical activity in people with MS report a high number of dropouts and have identified that participants struggle to maintain participation in activity intervention. As non-adherence and drop outs of these programs hinder the benefits of exercise as previously outlined, it is therefore valuable to enhance our understanding of what keeps patients engaged in a support program.

Therefore the aim of this study is to investigate what factors, psychological and social, are influencing exercise participation for people with MS and helps them to stay engaged in exercise programs.

If you consent to take part in this research study, it is important that you understand the purpose of the study and the interview you will be invited to attend. Please make sure that you ask any questions you may have, and that all your questions have been answered to your satisfaction before you agree to participate.

What the Study will Involve

To participate in this study you must be minimum 18 years of age and have been diagnosed with MS. If you decide to participate in this study, you will be asked to complete the following tasks:

- To volunteer for an interview asking you about your opinions and views in regards to your exercise participation. You will be able to read through the interview at a later date and provide feedback.

The Interview should take between 30 min-1 hour.

It is a slight possibility that you may experience some level of anxiety or stress during the session as a result of some of the questions. If this is the case feel free to skip this question, take a short break and continue at a later stage, or talk to a friend or a family member that is available to you. You are free to withdraw at any time during the session.
If these feelings persist after the completion of the session, we will arrange counselling support for you from Beyond Blue.

**Voluntary Participation and Withdrawal from the Study**

Your participation in this study is entirely voluntary. You may withdraw at any time without discrimination or prejudice. All information is treated as confidential and no names or other details that might identify you will be used in any publication arising from the research. If you withdraw, all information you have provided will be destroyed.

**Benefits of the Study**

It is possible that there may be no direct benefit to you from participation in this study. You will however have the opportunity to self-reflect on your current relationship to exercise and consider how moving through some exercise barriers you may have can provide new benefits in managing your MS symptoms.

While there is no guarantee that you will personally benefit, the knowledge gained from your participation may help others in the future. This is a relative new area and as such any light that we can shed on this topic will be beneficial to both clinicians, clients and MS support groups involved in helping people deal with MS.

If you have any questions about this project please feel free to contact either myself, Mohini Sacha on mob. 0402-400046, or my supervisors, Dr Yvonne Learmonth, ph 08-96606373 and Dr Brody Heritage ph. 08-93606547. My supervisors and I are happy to discuss with you any concerns you may have about this study.

**Feedback**

Once we have analysed the information from this study we will put on our website the summary of our findings. You can expect to find this feedback available in December 2017 on the following link http://www.murdoch.edu.au/School-of-Psychology-and-Exercise-Science/Research/Psychology-Research/Research-results/. The complete thesis will be provided to MSWA as well.

If you are willing to consent to participation in this study, please complete the consent form.

Thank you for your assistance with this research project.

Sincerely

Mohini Sacha, Dr Yvonne Learmonth & Dr Brody Heritage

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**Interview Schedule**

Let’s talk about your experiences with physical exercise programmes as a person with MS.

1. What is important to you in relation to exercise services for people with MS?
2. What factors in your life are helpful to you in attending an exercise programme here at MSWA?

Follow-up probes to elicit content on predicted psychosocial factors related to participation/attrition:

a. What are the factors that ‘stick’ or ‘glue’ you into the exercise programme, and encourage you to keep attending? {NB: Embedding factors}
   i. How do you think the exercise programme fits with what you want out of your MS treatment? How does it meet or not meet your expectations of what you want out of participating in physical exercise? {NB: Fit}
   ii. How do the social aspects of the exercise programme encourage you to stick with it? {NB: Links}
   iii. Do you feel like you would miss important things if you decided to stop participating in the exercise programme? What kinds of things would that be? {NB: Sacrifice}

b. Do you think other people telling you to attend the physical activity programme, or avoiding the consequences of not attending the programme, is relevant to your attendance? [If yes] Can you tell me a bit more about that? {NB: Self-determination theory; controlling factors}

c. How do you think the importance you place in participating in physical activity programmes, or the enjoyment you get out of it, has an influence on your attendance? {NB: Self-determination theory; autonomy factors}

d. [Note: This may have already been addressed in 2c; if underdeveloped then use this probe] How do you think participating in exercise programmes, like the one at MSWA, might be able to help you with your MS symptoms? {NB: Theory of Planned Behavior, behavioural attitudes}

e. Do you think that most of the people who are important to you approve of your participation in physical exercise programmes such as the one at MSWA? Why do you think that is? {NB: Theory of Planned Behavior; normative attitudes}

f. Do you think most of the people who are like you would participate in physical exercise programmes such as the one at MSWA? Why do you think that is? {NB: Theory of Planned Behavior; normative attitudes}

g. Do you feel confident in participating in physical exercise programmes, such as the one here at MSWA? Why do you think that is? {NB: Theory of Planned Behaviour, perceived behavioural control attitudes [self-efficacy]}

h. [Note: This may have already been addressed in 2b; if underdeveloped then use this probe] Do you feel that participating in physical exercise programmes, such as the one here at MSWA, is something that is up to you? Why do you think that is? {NB: Theory of Planned Behaviour, perceived behavioural control attitudes [autonomy/control beliefs]}

○ Are there any other factors in your life that might be important to consider when it comes to attending physical programmes, besides what we have talked about already?

3. What kind of support do you want and need (from friends, family or your MS healthcare provider) in order to participate in exercise programmes?

Thank you, is there anything else you would like to say on this matter?

Appendix H

Transcripts
The transcripts were a big file including over 130 pages and therefore could not be included here. For a full view of the transcripts, please go to:

https://www.dropbox.com/sh/1o2ej8cqwkkpsf2/AACF9MyWZgrUerx1XubDXxaDa?dl=0

Appendix I
Examples of Analysis
getting weaker I was noticing It was harder for me to keep my arms up, so then with the strength work doing the arm work I now... then now I can do longer hours. I can work evenings, all that strength work has helped me. And I'm far more confident than I have ever been. I, I lost my confidence, going back now five years ago, I had no confidence. I didn't think I was able to do anything cause I felt weak, weaker and I didn't think I was able to go to Bali with my sister. And I went oh... I don't know if I can go and do the shopping that they wanna go and do and I don't want to hold them up going shopping, going on a holiday. So I never would go with my sisters. Then I went one year I said no I gotta go and try and I went, and I shopped more than they did (Laughter). So there was a great thing, that was something that built my confidence and I realized that the strength work that I've been doing has now given me hope that I can do other things. And now I just work, I can work as many hours as I want. I'm so much happier, because people don't realize that you think that even though you have a debilitating disease, uh... but their own, uh, your nerve ending pathways and I don't know if I'm saying it correctly, that can be created for you to have new pathways to create um... other muscles to strengthen in a different way. So then you will become stronger in all different ways. But people don't think that they can get stronger, they just think they are going to get worse and worse and worse, and when they put that in their minds, they are not going to get better. They gotta have a positive mind, a positive outlook to think I can get stronger, because each day, each week I do the strength work, you think its not working, it's working, and I'm getting stronger. You can, I know with my clients and with my family and... and I'm happy and with my children too you know, you can do the activities you think you cant do, Oh ? I can't go run a marathon, which I like to, I can't go run a marathon but I'm happy if I can do my everyday stuff without having anyone to help me, I'm really happy. And that is to me, that's my help, assist, doing my clients hair, has made, my work has made me feel um, has pushed me to, to do these things that's, to talk about it all the time. I talk about it with people and, it just has strengthen me in so many ways. I think people don't realize the power of talk and the power of saying what's important and this is why I had to come and see you after I saw the brochure. It's because people need to know they can get strong. Even though they have a debilitating disease, because you don't really get much out of your doctors, they tell you the... the facts and the... and the aa... you know like a... I don't know this technical term, wouldn't know the technical terms. I just know, I'm just a basic um... you know, trade person that loves her job. I don't know the technical terms about the MS terms, about the neurological pathway or this and that and the other and you got a debilitating disease what does this mean, you know. I didn't know what it mean, I didn't know but they went... No one tells you... you need to strengthen. One thing someone told me many years ago, this was not many years ago but like, over ten years ago when I was diagnosed cause I asked a lady, one of my friends aunties about a, um... how are you going with your MS? And she said, whatever you do, which resonated with me, whatever you do, exercise. And because I had children there was no time. I had two, you know little kids at home it's impossible, um... and once my kids started school I was able to then you know... book a time... make it. Like its that commercial that says, um... Commit, um... act, commit...commit, act... or it's basically that you go and commit to something and it's for depression, but if you commit to something and you book
of people through the MS society. Um and even the people that are doing their physio you know we chat and now we even get together at each others houses and having coffee and cake and it's then gone from the exercise to the social outside of that group.

I: Ok, that's nice.

P: We can, you know, I connected with a couple of the women there, so you know we are going out to each others houses and meeting and planning that we may go away somewhere together cause we all... one lady got a stroke, another lady is like me in a wheelchair with MS, so you know we all know what we are dealing with. So you kind of know what we are talking about. So yeah, we got that connection so, yeah.

I: Do you share about your experiences with MS and having that disability or...

P: Oh, most definitely, yeah yeah, yeah we say something and I'll say to my friend (name), oh what's that lady's name, I've forgotten her name, because she has been in the group longer than I have. She tell me and we all understand that we forget things and you know it's hard for us to remember and we do silly things and have accidents when we fall over and do, so yeah we understand and don't need to go into big explanations as to other people. We just know.

I: That's very special to have these mirrors.

P: Exactly, yeah, yeah.

I: So if, how do you feel if... do you feel that you would miss... if you would stop your exercise programme? You know, definitely I already know your answer but I want to ask you anyway, if there is anything you want to add there? Do you feel that you would miss some of these important things if you would stop the exercise programme?

P: Oh most definitely, yeah, no, I would be devastated. Yeah I would be, you know, as I say to some people you know, I know this sounds weird but you know I love going to exercise, because as I said it's the whole package. I get so much out of it. And, um, I lived in new south wales before and I didn't have any of this. I didn't have any of the opportunity to um, get involved in it. And now that I'm involved in it I know what I've been missing. You know I like going there and its not only because the exercise it's the whole... the whole package like you are taking to the professionals like the physio and all that, and they all understand and then you get you know all you support workers that come once a month. I'm now staying there doing the lunch you know, so we after the exercise some of us sit down and have a lunch, that we get prepared for us and everything so yeah, no, so if they say we are closing the MS society down in western Australia and you can no longer come down to the physio then yeah I'd be totally devastated.

I: Yeah I understand. It sounds like it's a life essential
<table>
<thead>
<tr>
<th>Themes</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive</td>
<td></td>
</tr>
<tr>
<td>1. Improves daily functioning (in the little things)</td>
<td>2, 11, 1, 9</td>
</tr>
<tr>
<td>2. Social Important</td>
<td>2, 11, 1, 4 (females), 8, 9, 12</td>
</tr>
<tr>
<td>3. Exercise at MSWA linked to motivation to do exercise at home</td>
<td>2, 12, 11, 9</td>
</tr>
<tr>
<td>4. The understanding and support from the physios (aware of the abilities and disabilities and limitations, targeted and focused assistance, monitoring, keeping track and noticing changes) (don’t get that from doctors or neurologists) Week to week support and following up</td>
<td>2, 3, 1, 4, 9, 11, 12</td>
</tr>
<tr>
<td>5. Benefits after starting keeps you going</td>
<td>4, 11, 9, 12</td>
</tr>
<tr>
<td>6. Improved Strength</td>
<td>9, 1, 4, 7, 8, 11, 12</td>
</tr>
<tr>
<td>7. Healthy Fear if I stop its got to get you</td>
<td>8, 11, 5, 7, 12</td>
</tr>
<tr>
<td>8. Taken awhile to realize that you do need to exercise</td>
<td>11, 9</td>
</tr>
<tr>
<td>9. Your mindset important, importance I put on it, determination</td>
<td>11, 9, 13, 2, 3, 5, 8, 10, 12</td>
</tr>
<tr>
<td>10. Builds Confidence</td>
<td>9, 11</td>
</tr>
<tr>
<td>11. Loosing weight or wanting to</td>
<td>11, 5</td>
</tr>
<tr>
<td>12. Diet</td>
<td>11, 13</td>
</tr>
<tr>
<td>13. Routine, Regularity, continuity</td>
<td>11, 9, 2, 6</td>
</tr>
<tr>
<td>14. Uplift the mood, more positive, counteracts depression, feel good</td>
<td>13, 9, 1, 6, 7, 10, 11, 12</td>
</tr>
<tr>
<td>15. Keeps me more positive about my disability</td>
<td>1, 9</td>
</tr>
<tr>
<td>16. Maintenance of current functions and abilities and not getting worse, Managing the condition</td>
<td>2, 1, 5, 7, 8, 9, 11, 12</td>
</tr>
<tr>
<td>17. Much more able than I was</td>
<td>11, 9, 12</td>
</tr>
<tr>
<td>18. Get out of the house and do something</td>
<td>8, 1</td>
</tr>
<tr>
<td>19. Happy with what’s offered at MSWA</td>
<td>11, 9, 2, 1, 3, 4, 12</td>
</tr>
<tr>
<td>20. Keeps my body moving, mobility, stretching, flexibility, balance</td>
<td>1, 2, 3, 5, 7, 9, 11, 12</td>
</tr>
<tr>
<td>21. Satisfaction after exercise, been doing something good for myself, accomplishment, Purpose.</td>
<td>1, 5, 6, 8, 9, 10, 11, 12</td>
</tr>
<tr>
<td>22. Enjoying exercise or stretches</td>
<td>1, 2, 5, 7, 9, 10</td>
</tr>
<tr>
<td>23. Driving support (driver, company)</td>
<td>1, 4</td>
</tr>
<tr>
<td>24. Feeling SAFE to exercise or by Physios support and guidance</td>
<td>1, 2, 3, 4, 6, 7, 9, 12</td>
</tr>
<tr>
<td>25. Improved general well-being from the whole package (exercise, physically moving, the social aspect of the group)</td>
<td>1, 2, 4, 5, 8, 9, 11, 12</td>
</tr>
<tr>
<td>26. Got (new) friends who understands</td>
<td>1, 2, 9, 12</td>
</tr>
</tbody>
</table>

Appendix J
Summary of Project

**Researchers:**
Mohini Sacha (honours student) and Dr Brody Heritage and Dr Yvonne Learmonth (supervisors)

**Title:**
Factors influencing Motivation and Retention of people with Multiple Sclerosis in Exercise Activity: a qualitative study

**Ethics Approval number:**
2017/081

**Month and Year:**
November 2017

**Description and the Aim of the Research:**
Multiple Sclerosis (MS) is a progressive chronic disease of the central nervous system affecting 23,700 Australians. A growing body of evidence confirms the benefits of physical exercise for people with MS. Exercise training is today considered to be the single most effective non-pharmacological treatment for MS and is part of many effective rehabilitation programmes. As non-adherence and drop-outs of these programmes are high and hinder the benefits of exercise, it is important to enhance our understanding of what motivates persons with MS to engage in exercise programmes overtime, and especially what specific factors facilitate retention.

This study used four well-established theories such as social cognitive theory, theory of planned behaviour, self-determination theory and job embeddedness theory to assist in the understanding of motivational processes underlying exercise behaviour. On this basis, the aim of the study was to examine “What are the psychosocial factors that predict participation and retention in exercise activity and support programmes for people with Multiple Sclerosis?”

**Method:**
Participants were recruited through the Multiple Sclerosis Society of Western Australia (MSWA). Fifteen participants (twelve women and three men) were included in the study by meeting the criteria of being above 18 years of age and having an MS diagnosis, with an age range of 42 to 73 years. The level of disability in motor and ambulatory dysfunction was measured with the Patient Determined Disease Steps (PDDS) scale. All participants took part in a semi-structured interview lasting between 25-60 minutes either in person at MSWA or over the phone. They were asked about their experiences with exercise activity as a person with MS. The interviews were analysed using thematic analysis.

Research Findings:
This study identified three themes, attitudes about purpose, improved wellbeing and an opportunity for connection and support that were found to influence motivations and enhance participation in exercise activity. Thoughts about purpose such as managing MS, maintaining functions and independence, the hope of improvement, being a positive influence on others and the commitment and determination to that purpose, as well as an improved day-to-day functioning facilitated participation and retention in exercise programmes. Further, exercise provided persons with MS an opportunity to get out of the house and being part of their community with others, meeting new friends who understand and receive support. The combined forces of these factors and individual characteristics influenced a person’s embeddedness or attachment to their exercise activity, and their decision of whether to stay or leave. The combined constructs from the four theories were found useful (REQUIRED). 674742

Inform clinical interventions of factors implicated in participation and retention as well as what they need to address in order to retain a high number of participants in their exercise programmes.

Appendix K
Extension Approval Form
able to function at all but mainly bedridden. The hardest part for me is of course the writing up of the thesis as it needs a working brain with a clear thinking. Something I don’t have at the moment more than in short periods of time. Therefore it all goes very slowly for me. I’m attaching my medical certificate from my doctor as well as a letter from Equity. Supratik Mukherji, the Equity wellness officer is well aware of my disability as I have had to be away from my studies at Murdoch for 2.5 years due to being very sick before I did resume my studies at the beginning of 2017. I did have periods during this winter where I was much worse and couldn’t do any study at all on my thesis for many weeks in a row and was worried I wouldn’t be able to complete it at all. But luckily I have improved to be able to pick it up again. If you need a more specialized medical certificate please let me know as I can arrange that.

Kind Regards Mohini Sacha
Conditions of Extension Request Application

- Extension request applications must be submitted before the due date, preferably significantly before.
- Hard copies and LMS submission of theses must be complete by 12pm on the revised due date.
- If an extension is granted, the submitted thesis must have this completed form attached.

I have read and accepted the conditions of this application:

Student’s name (please print) Mohini Sacha

Student’s signature

Date: 3 October 2017

Section 2 (Supervisor to complete)

Supervisor

- Do you support this application and the length of the requested extension? Yes No

Supervisor’s name

Supervisor’s signature Date: 9/10/17

Comments:
Section 3 (Unit Coordinator to complete)

Unit Coordinator

Outcome: ___Denied

☑ Approved in full, new due date: 6/11/17

___Approved in part, revised due date: _____________

Unit Coordinator’s signature: ___________________ Date: 10/10/17

Comments:

__________________________________________

__________________________________________

__________________________________________