

THE ROLE OF EXERCISE IN NEGOTIATING AN IDENTITY AS DISABLED: A  
QUALITATIVE EXPLORATION OF THE EXPERIENCES OF INDIVIDUALS WITH  
MULTIPLE SCLEROSIS

BY

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## **ABSTRACT**

**BACKGROUND:** Multiple sclerosis (MS) is a chronic condition resulting in a wide range of physical, cognitive and affective impairments that can either fluctuate, or remain and worsen depending upon the disease course. The episodic nature of symptoms in relapsing-remitting MS (RRMS) results in an in-between or liminal embodiment; situated in-between sick and well states, ‘able-bodied’ and disabled. Because of this, MS has a tenuous relationship to the field of Disability Studies and mainstream disability activism. Furthermore, the recent surge in research on the impact of exercise/physical activity (PA) participation on symptoms and quality of life among those with MS has shifted exercise and PA promotion to individuals with MS in ways that reinforce ableist ideas about the human body (e.g. for managing or minimizing impairment/disability). This increasingly medicalized version of exercise promotion can cause increased guilt over inactivity, and result in constrained views of PA that may be compounded by the uncertain nature of having MS and negotiating a disabled identity. Thus, it is important to further explore the relationship between MS, exercise and Disability Studies.

**PURPOSE:** This dissertation explores the myriad and contradictory ways that individuals with MS perceive exercise and physical activity as part of their self-care, as well as the ways that exercise and physical activity are used to negotiate an identity as disabled.

**METHODS:** The aims of the current analysis are to explore the roles of exercise and physical activity in their MS management and prevention of disability. I use Interpretive Phenomenological Analysis (IPA) to analyze interviews from two previously conducted qualitative research projects related to exercise and MS. The first (RELAPSE) is an exploration of the experiences and concerns related to physical activity of individuals with MS following a

relapse. The second study (PEMS) is a photoelicitation project focusing on the people, places, and things that influence physical activity behavior among adults with MS.

**RESULTS:** I identify eight themes relevant to my original research questions which are organized into three categories: Exercise, Identity, and Disability. The Exercise category describes orientations to exercise as a disciplinary activity, as promoting self-transformation and social engagement, and as medicine for managing MS and for self-care. The Identity category describes notions of fractured self-concept across a multitude of dualisms, as well as the ambiguity of embodied experiences relative to health and disability. The Disability category explores experiences with and perspectives of ableism, the use of assistive devices, and the development of a disability identity. Overall, participants describe many different roles that exercise occupies for them, as well as different orientations and motivations for engaging in exercise. This contributes to a fractured self-concept across a variety of continuums, including mind/body, old self/new self, MS self/true self, and healthy/unhealthy. The relationship between exercise and disability identity was also complex and contradictory, including using exercise to push away from or reject a disability identity and minimize visible impairment; or using exercise to recognize ableism, structural disablism, and develop a political disability identity; and using exercise to adapt to and prepare for situations inhospitable to disabled individuals.

**CONCLUSIONS:** Contextualizing these results within the Social Relational Model of Disability, exercise is used by individuals with MS to manage impairment in positive ways but contributes to psycho-emotional disablism by reinforcing compulsory ablebodiedness. Because of the uncertain and liminal characteristics of MS, exercise seems to occupy several contradictory roles that both challenge compulsory ablebodiedness and reify it. Therefore, this study supports the need for addressing problematic aspects of exercise promotion paradigms that contribute to

compulsory ablebodiedness while preserving and building on positive benefits of exercise. I propose an alternative exercise promotion paradigm where emphasis shifts from exercise as discipline towards exercise as a resource. Some may wish to use exercise as a resource to navigate and alleviate aspects of their disability and impairment, while others who are working towards affirming their descriptive disability could participate in exercise for reasons other than to change their embodiment. This paradigm has implications for other chronic disease and disability populations.

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## PREFACE

This dissertation draws from vastly different disciplines in the life and behavioral sciences, social sciences and humanities. As such, the language I have chosen to use represents several tensions which I wish to acknowledge upfront. First of all, I have had to grapple with question posed by Critical Disability Studies scholar Nirmala Erevelles:

What is my relationship to disability? With what authority can I speak about disability? And why? Am I speaking with disabled people or about them?... Disability studies' eternally changeable borderlands make these questions relevant to everyone, whether they identify as disabled or not at any given time. And just in case someone argues to the contrary, belonging and identity are not idle insertions into political discourse; rather they have critical implications for how the field of disability studies continues to expand and thrive within a future that is, as yet, tentatively unimaginable and tantalizingly possible. (Erevelles, 2014)

I inhabit many privileged positions in our current sociocultural moment, not least of which is able-bodied (by many Western standards). I however identify *with* the population of those with MS given my proximity to their lives for the last 4 years. My participants have become my friends, my support system, and often motivation for continuing my academic pursuits. I have attempted to foster relationships of reciprocity, my latest endeavors to provide free community-based exercise programs have been just one element of this reciprocity. I do not have MS, yet, I invest my time and effort to *belong* to this community. I have engaged in, read, and/or analyzed over 100 interviews with individuals with MS. My own speaking within this field is inextricably linked with all I have heard. I recognize my tenuous relationship to the field, even as I forge a way into this field with the voices of those who have entrusted their stories to me.

I have chosen to use the concept of rhetorical adjacency in my attempts to foreground the voices of (dis)abled persons with MS in this dissertation. Pryal defines rhetorical adjacency as “rhetorically positioning oneself *beside* the [disabled person] and resisting the urge to dominate

her life story.” (Emphasis original, [] represented neuroatypical person in original) (Pryal, 2015).

In my attempts to make change in exercise promotion discourse, I have conversed with many persons with MS who feel a sense of empowerment from engaging in the very discourses that I intend to critique. I have had to resist the urge to think of my work in terms of ‘emancipating’ individuals from harmful practices and instead foreground their experiences and interpretations of those experiences in my discussion and critique. My ultimate standard has been: would the participants feel well-represented if they read this dissertation?

Secondly, I have encountered a difficult tension in writing styles between several of the disciplines from which I draw. Fitzgerald and Callard discuss the difficulties of navigating spaces between cognitive neuroscience and social sciences/humanities. They put forth the concept “experimental entanglements” to encourage moving beyond interdisciplinarity in collaboration and writing. Specifically, they discuss joined writing where collaborators from different fields avoid falling into old models reinforcing standard divisions of labor and instead “shift each collaborator into labouring within the prescribed space of the other collaborator.” (Fitzgerald & Callard, 2015, p. 22).

I, myself am engaged in joined writing. I have labored within the space of many disciplines as I have engaged in scientist and social scientist roles throughout my studies. I have chosen to loop medical, material, critical and social perspectives throughout. My efforts to promote exercise for a population with a chronic disease reflect my acknowledgement of the physical, mental and psychological benefits of exercise. However, my understanding of the complicated histories and social constructedness of disability and fitness give me pause and trouble notions of rehabilitation at all (i.e. society needs rehab, not disabled individuals).

Littlefield, et al. describe this type of tension as ‘disciplinary double consciousness.’ More specifically, they define disciplinary double consciousness as the “dissonance experienced (cognitively, affectively, conceptually, or otherwise) by being caught between a “home” discipline and a position as a scholar on an extended deployment in some secondary discipline...” and affirm that “collaboration does not stop at the boundaries of the body – it is an interior process of churn too...” (Littlefield, Fitzgerald, Knudsen, Tonks, & Dietz, 2014, pp. 3-4).

This dissertation represents my deployment into Disability Studies from my home discipline of Kinesiology and the product reflects my interior collaboration; holding these two fields, their strengths and weaknesses, in tension. I have used this dissertation to explore the ‘entangled’ and ‘tantalizingly possible’ futures and implications for both fields.

## **CHAPTER 1: MS AND DISABILITY**

In this chapter, I explore the material, social and individual aspects of MS embodiment in order to elaborate on different models of disability and disability identity formation. Within the context of MS, embracing a disability identity that is politically transformative and individually empowering is complicated by the fluctuating course of impairment that individuals with MS experience. Using Thomas' Social Relational Model of disability, as well as Vick's notion of episodic disability and Mingus' concepts of descriptive and political disability, I argue that the nature of MS embodiment adds important insight into how individuals with chronic illness can develop an identity as disabled and the individual and disciplinary possibilities that might emerge.

### **An Ambiguous Place: Terms and Definitions**

The framing of multiple sclerosis (MS) varies between fields and professionals and has evolved over time. Once considered an atypical palsy, the name — multiple sclerosis — reflects the dominance of pathophysiological understandings of disease by foregrounding the physiological manifestation in the naming of the condition. The debates regarding definitions of disease, sickness, illness, disabilities, and impairments are well-worn (see Hofmann, 2016) and will not be addressed here. However, I will use these terms to frame different perspectives that influence the experience of a person diagnosed with multiple sclerosis in the US context as they are all part of the milieu of input (i.e. physiological/material, social and phenomenological). My purpose here is not to debate the meaning of these terms, rather to make apparent the liminality of those with this diagnosis across these distinctions. I will frame this first section in terms of disease (description of the material), sickness (description of social construction of disease), and illness (description of phenomenological experience with disease and sickness) as discussed by

Boyd and others in the fields of medical sociology and anthropology (Boyd, 2000). I will then contextualize this discussion within the field of Disability Studies. As a caveat, I fully acknowledge that my descriptions of the material manifestations of disease are influenced by sociocultural understandings of disease, normalcy, health, medicine and disability.

### **Disease, sickness, illness: The world of multiple sclerosis**

The *disease* is the same demyelination everywhere... but the *sickness* and the *illness* aren't the same everywhere. *Sickness* is the word that medical social scientists use to designate the social construction of the biological *disease*. The distinction allows for culturally different responses to *disease* while avoiding claims of radical culturalism (that the representation is the only reality of *disease*). *Illness* is the individual course of the disease, obviously under the spell of both personal biology and cultural difference at the same time... The *disease* itself has a history that interacts with these social and individual dimensions. The *disease* is not the same everywhere. It is affected by different genetics, environment and diet; by different development in the child and the adult; and by different diagnostic standards. There is a world of multiple sclerosis... (Swiderski, 1998, pp. 5-6).

**Disease (material).** Multiple sclerosis (MS) is a neurological disorder of the central nervous system (CNS). The etiology of MS is largely unknown, but presumably involves an autoimmune disease trigger by the environment in genetically susceptible persons (Compston & Coles, 2008). The disease course is typically characterized by periods of immune-mediated degradation of the myelin sheath coating axons in the CNS. This results in a variety of symptoms, depending on the location of demyelination and transection of axons within the CNS (Lucchinetti et al., 2001).

There are several categories of MS symptoms, and these include physical, cognitive, and affective, as well as fatigue. The physical symptoms common in MS are spasticity, muscle weakness, loss of sensation, loss of bowel and bladder control, sexual dysfunction, and loss of mobility (Confavreux & Vukusic, 2006; Forbes, While, Mathes, & Griffiths, 2006; Kurtzke, 1983; Lublin & Reingold, 1996; Mills R.J., Young C.A., Mills, & Young, 2008; Prakash, Snook,

Lewis, Motl, & Kramer, 2008; Samkoff & Goodman, 2011). Cognitive impairment is a common symptom in MS resulting in slowed processing speed and learning and memory loss. The most common affective symptoms are depression and anxiety (Beal & Stuifbergen, 2007; Korostil & Feinstein, 2007; Sadovnick et al., 1996; Siegert & Abernethy, 2005). Fatigue is another symptom of MS which affects approximately 75% of all persons with MS (Hadjimichael, Vollmer, & Oleen-Burkey, 2008).

There are two main types of MS (further categorized into subcategories). Relapsing-remitting MS (RRMS) involves periods of relatively stable symptomology interspersed with relapses characterized by acute disease activity and increased symptom burden (Coles, 2009). Primary progressive MS results in increasing impairment from the outset of the disease inception with no remission of symptoms (Miller, Chard, & Ciccarelli, 2012). RRMS often develops into a progressive form of MS (secondary progressive) (Compston & Coles, 2008). Individuals in these categories of MS may experience a wide-range of disabilities as a result of the symptoms they encounter, but walking impairment is one of the most common and visible impairments associated with MS disability (Socie, Motl, Pula, Sandroff, & Sosnoff, 2013). An estimate of nearly 1 million individuals in the US have MS (NMSS, 2017b), with an approximate prevalence of over 2.3 million individuals worldwide (National Multiple Sclerosis Society, 2005a).

There is no known cure for MS, and disease-modifying therapies slow but do not prevent disease progression over time (Feinstein, Freeman, & Lo, 2015). There are also several symptom-specific therapies with various degrees of effectiveness (Cecile Donze, 2015). Treatment, loss of earnings, hospitalization, and (in)formal caregiving represent significant costs to the individual that have increased in the last twenty years (Chen, Chonghasawat, & Leadholm, 2017; Whetten-Goldstein, Sloan, Goldstein, & Kulas, 1998).

**Sickness (social).** Based in a western context, there are several key characteristics of MS as a socially-contextualized sickness that have been described: uncertainty, invisibility, passing and age of onset. These are characteristics of the disease course that are related to physiological manifestations of MS and influenced by social values, norms and ideals. I will describe these characteristics individually in this section.

*Uncertainty.* MS is a disease with an unpredictable course which contributes to increased uncertainty about what the future will bring. Fear of the future, what will come, how disabled/impaired a person will be in 1, 5, or 10 years reflects a deep, unquestioned and socially constructed need for certainty and control especially in Western cultures. There is research indicating that this uncertainty and loss of control in daily life may be the most disturbing problem among those with MS (Olsson, Lexell, & Söderberg, 2008).

Uncertainty in chronic illness involves many factors and unpredictability related to symptoms, diagnosis, treatment, relationships, disease progression and future planning (Dennison, McCloy-Smith, Bradbury, & Galea, 2016; Mishel, Padilla, Grant, & Sorenson, 1990). The impact of this uncertainty is dependent upon the degree to which uncertainty is disruptive to an individual's status quo:

As uncertain disease-related or illness-related factors are introduced into the person's life the uncertainty competes with the person's previous mode of functioning. If individuals could contain the uncertainty so it did not invade multiple aspects of their lives, the uncertainty would not be sufficient to disrupt an ongoing life pattern. But if aspects of uncertainty were to multiply so rapidly they invaded significant aspects of the person's being and life, then the impact of the uncertainty would move the person, a far-from-equilibrium system, past a critical value where the stability of the personal system or its independence from disruptive forces could no longer be taken for granted. (Mishel et al., 1990) p. 259.

The moment of MS diagnosis is consistently described by retrospective and prospective studies as highly emotional, distressing, anxiety-provoking, and those with MS are generally

dissatisfied with the information given at time of diagnosis (Solari, 2014). Prognostic uncertainty contributes to lasting distress even while the confirmation of an MS diagnosis often reduced anxiety in those seeking a diagnosis. This is reflected in an experience described by Cheri Register (Register, 1999) about someone who experienced symptoms of MS for 5 years before receiving a diagnosis during which time her experience of those symptoms was invalidated by the medical community and her social sphere. She describes the day of her diagnosis:

And with that came this wonderful sense of relief. I giggled and laughed. I was joyous. My husband was the same way. We were just like two kids running through a park. We had a name to something. We could deal with it. I was not a neurotic lady. It was OK to slow down, to quit work. It was OK to say no to things. (Register 1987, p. 5).

For the person with MS who has experienced or is experiencing this kind of invalidation, it may result in a new contradiction. A person must now grapple with the need for a diagnosis to be validated and the desire to distance themselves from the diagnosis to maintain his or her self-identity (Wendell, 2001). Furthermore, the uncertainty of not knowing what to call your symptoms prior to diagnosis becomes replaced with the uncertainty of not knowing your prognosis with MS (Koch, Jenkin, & Kralik, 2004; Koch, Kralik, & Eastwood, 2002; Olsson et al., 2008).

Hence diagnosis also entails various levels/degrees of uncertainty, both in its desirability and impact. Wendell poses the question related to these types of experiences with uncertainty and diagnosis: ‘How can I remain connected to a world that denies I am in pain, or dizzy, or nauseated, when I myself cannot deny that I am (or can deny it, but only at the cost of distrusting what is present to my consciousness most of the time?)’ (Wendell, 1996). A diagnosis is equated to permission to seek out accommodations and acceptance but until that is received (and frankly often after it is received) society cannot grant such accommodations.



*Invisibility, Passing and Episodic Disability.* RRMS involves fluctuations in symptoms and impairments, many of those impairments representing what Hirschmann calls *endemic* invisible disability i.e. impairments that cannot be seen (Hirschmann, 2015). Numbness, tingling, fatigue, cognitive impairment, depression, hearing loss, and vision problems among other MS symptoms are endemically invisible though there may be visible cues. There are many whose symptoms are outwardly invisible for the majority of their experience, although these symptoms might be quite distressing. However, people with MS may also exhibit visible symptoms (e.g. walking impairment) intermittently or fairly constantly.

Additionally, *voluntary* invisibility defines situations where impairments are not by their nature visible and therefore the individual has the option to disclose or not to disclose any impairment or diagnosis. Those with impairments of this nature may be inclined to this voluntary invisibility so as to avoid disabling attitudes (Hirschmann, 2015). However, individuals with MS may experience what Moore describes as ‘leaking,’ a phenomenon where third parties mine bodily data and draw conclusions about the person based on this bodily data. For example, in MS, a person who has chosen not to disclose their disease might walk with gait impairment and this bodily information can be interpreted in a multitude of ways by third party observers (Moore, 2010). In a study regarding the stigma of MS, many participants described a desire to disclose MS clearly in public situations to avoid the stigma of being considered ‘drunk’ (Grytten & Måseide, 2005). This represents a complex position, between stigma of disease and disability and stigma of other socially unacceptable modes of being (e.g. drunkenness in the case of walking impairment or slurring of speech, laziness in the case of fatigue). Both stigmatizing attitudes can result in the withdrawal of the individual from social situations (Grytten & Måseide, 2005; Hirschmann, 2015). This phenomenon or state of voluntary invisibility (also

known as “passing”) can be emotionally taxing and in some cases reflects aspects of internalized oppression, i.e. where a person of a disadvantaged group assimilates prejudices of the majority group against the disadvantaged group of which they belong (Reeve, 2002).

***Onset.*** MS typically has an onset in early adulthood (Compston & Coles, 2008). Thus, the memory of an “able body” and previously held beliefs and stigmas must be faced by the individual with MS. Consequently, this often entails a process of identity confusion and restructuring (Irvine, Davidson, Hoy, & Lowe-Strong, 2009). Individuals with MS often face a restructuring of self-hood and identity to accommodate shifting abilities and roles (Irvine et al., 2009; Lexell, Lund, & Iwarsson, 2009; Mozo Dutton, Simpson, & Boot, 2012). They may embrace a new identity or reject it and seek to carry on as if nothing had changed (Barker, das Nair, Lincoln, & Hunt, 2014). Furthermore, they have the memory of an able-body and pre-diagnosis attitudes and beliefs about disability and disease which must now be confronted and challenged (Reeve, 2006). Bombardier et al provide evidence that when chronic condition occurs at younger ages, the trauma is greater and individuals are more likely to experience depression rather than benefit finding (Bombardier, Ehde, Stoelb, & Molton, 2010). MS is a condition which presents at a younger age (mid-thirties) than many other chronic conditions and therefore may result in greater trauma and depression. There is indeed evidence that individuals with MS have higher rates of depression (an estimated lifetime prevalence of around 50%) than those with other chronic conditions, even those resulting in similar disability (Schubert & Foliart, 1993).

***Illness (phenomenological).*** This final section will briefly focus on the individual experiences with sickness and disease as described above using phenomenological research conducted within this population.

Self-perceptions of individuals with MS have been studied extensively (Barker et al., 2014). Mozo-Dutton et al interviewed individuals with MS and asked about the ways they perceived themselves. They discussed three themes from there IPA analysis, namely separateness from the body, changing relationship to self, and moving on and living with MS (Mozo Dutton et al., 2012).

In this and other studies, feelings of separateness from the body were described. This included the experience of knowing something was wrong before having a diagnosis of MS, feelings of betrayal by the body; that their bodies could no longer be depended on. The idea of alienation from self has been explored by several scholars in disability studies. Zaner writes:

We are led eventually to the conviction that our everyday, life-worldly understanding and experience of our own alive bodies are fundamentally wrong, specious and thus to think that our own most fundamental experiences are yet fundamental deceptions. Not trusting ourselves, thus, we perforce are led to place our trust in others-in experts in the body-to tell us about ourselves. (Zaner, 1983) page 139.

It is argued that this process happens mostly in the context of medicine. In the case of MS, as described by the participants in the study by Mozo-Dutton, the process of receiving a diagnosis can be one which alienates people from their bodies but also can be empowering for some individuals who have felt alienated from their bodies as they experienced symptoms with no name, no explanation, and no validation of their experiences. They may be told variations of ‘we don’t know what’s wrong with you’ or ‘there’s nothing wrong with you’ before finally having confirmatory evidence (usually through an MRI, passage of time events and episodes) that they have MS. The sentiment of being an inexplicable medical enigma calls into question the veracity of the person’s lived bodily experiences. As Zaner points out, this process leads a person to put more trust in experts to tell him or her about his or her body than his or her own embodied experience. Furthermore, since the presentation of symptoms is so varied in MS, those with a

more ‘non-traditional’ experience may be even more likely to put more stock in the medical authorities with whom they interact than their own experience. Biomedicine privileges the quantified, objective measures derived by technological means to examine and explain the human body over the subjective experience of the patient or even the clinical examination of a practitioner (Thornquist & Kirkengen, 2015).

Individuals with MS often face a restructuring of self-hood and identity, the second theme of Mozo-Dutton’s study. They may embrace a new identity or reject it and seek to carry on as if nothing had changed (Barker et al., 2014). Furthermore, they have the memory of an able-body and pre-diagnosis attitudes and beliefs about disability and disease which must now be confronted and challenged.

MS symptoms are reported to cause a great deal of both physical and emotional distress. Kralik et. al report that women with MS describe a feeling of betrayal by their bodies. This reflects the bio-social interaction of expectations about how bodies *should* act and how they *do* act (Koch et al., 2002; Kralik, Koch, & Eastwood, 2003).

This section detailed the material, social and phenomenological facets of MS in order to give context to the various models of disability which have been proposed in the last few decades. The models I will now discuss vary in degrees of engagement with and explanatory power of this population and others similar to it.

## **Disability Studies and MS**

To begin I will outline the history of Disability Studies in order to provide a historical context for the models of disability which I will discuss and frame the importance and explanatory power of the model I will use to frame this dissertation.

For over 30 years, Disability Studies has emerged as an academic field in response to and rejection of dominant medical models of disability which locate the “problem” of disability within the individual. According to medical models of disability, individuals were treated as both socially deviant, and as under the purview of the medical realm (or psychiatric realm), on the basis of physical, mental or emotional difference. While this view of disability is still pervasive among healthcare professionals and many in western cultures, the social model of disability was officially introduced in 1976 with a position statement by the Union of the Physically Impaired Against Segregation (UPIAS). This statement challenged the traditional individual/medical view of disability and argued that disability is a result of structural barriers that people with impairments faced in society. Thus disability is a result of societal barriers, not physical, mental or emotional impairments (UPIAS, 1976). In this early form of the social model (as discussed in greater detail by Oliver (Oliver, 1983)), impairment was distinguished from disability. Impairment is the reality of the physical or mental state of a person’s body/mind that to a greater or lesser extent is seen and treated as a medical issue or problem. Disability is then defined as structural and societal limitations of activity placed upon individuals with impairment. The introduction of the social model of disability was a pivotal moment in the history of disability, where activism in nations such as the US and the UK began to yield policy changes that would address the structural factors involved in the limitations and exclusion of disabled individuals. Starting at this time, the place of people with chronic disease in the disability rights movements was tenuous because disability would no longer be understood as illness under the social model of disability. In 1983, the United Nations changed their definition of disability to include impairment as a loss or abnormality of a psychological, physiological or anatomical nature, disability as restriction of ability to perform an activity (within the range of what is “normal”),

and handicap being the interaction between disabled individuals and their environment (i.e. “loss or limitations of opportunities to take part in the life of the community on an equal level with others” UN 1983: I.c. 6-7). The WHO developed the International Classification Framework to emphasize the complex interactions between physical/bodily structure, activities, functions, participation in society, personal and environmental factors (World Health Organization, 2002).

Many argue that the strength of this version of the social model of disability (i.e. the strong or pure social model) lies in the strict impairment/disability dichotomy and the emphasis on disability, not upon impairment. By emphasizing structural disability as politically relevant and deemphasizing personal impairment within the movement, the fear that impairment would lead to a reification of medical/individual models of disability could be assuaged. In the US context, the Americans with Disability Act was passed in 1990 and was a monumental change of policy that also served as a political acknowledgement of the tenets of the social model of disability.

Despite the political power of the social model of disability, it has been heavily critiqued for a variety of reasons, not least of which is the lack of engagement with the notion of impairment. Early feminist critiques argued that “the personal *is* political” and advocated that a social theory of disability could not ignore the lived experience of impairment. By the late eighties, feminist theorists such as Susan Wendell, Carol Thomas, Jenny Morris and others began to argue for the place of illness in disability (Thomas, 1999; Wendell, 1989, 1996). Prior to this, disability rights activism eschewed the inclusion of any mention of illness because of the desire to break from medical models of disability which previously defined those with disabilities as sick (Gill, 1994). Those with multiple sclerosis and other chronic diseases that result in physical, mental and emotional impairments had been left on the fringe, not part of the disability rights

movement because of their illness label. With these early critiques, those with chronic illness began to be part of the negotiation of new theories and models of disability. Wendell argued for a new dichotomy, i.e. unhealthy vs. healthy disability to both ease concerns of those who are disabled but regard themselves as healthy, not sick, and to give place for those who are impaired as a result of chronic illness and therefore tethered (whether willingly or unwillingly) to the medical realm. The unhealthy disabled have the potential to be a highly medicalized group of individuals. Chronic illness bears the potential for frequent medical appointments, pervasion of medical treatments/therapies into daily life, and loss of autonomy (whether real or perceived) to medical authority (Wendell, 2001).

Feminist scholars also began to scrutinize the gendered nature of disability, e.g. that women were often primary caregivers for children or other family members with disabilities, that women were more likely than men to suffer from chronic illnesses resulting in disability and that the oppression of women in the social sphere may be contributing to the experience of being disabled (Driedger & Owen, 2008). These discussions also critiqued mainstream feminism's lack of focus on the suffering body and emphasis on bodily control, something that may be lacking in those with impairments (Wendell, 1996). These critiques are relevant to the MS population as females are 3 times more likely to be diagnosed with MS than males and MS often results in a loss of control over a variety of physiological functions (e.g. walking, bowel and bladder function, sexual function).

Other areas of disability studies are emerging from critiques of the strong social model. Crip Theory, often closely associated with Queer Studies, was put forth by Robert McRuer as a way of challenging compulsory ablebodiedness, seeking to understand the construction of normal and illustrating the ways that "crip" has been reappropriated as a term of pride among

disabled individuals (McRuer, 2006). Patsavas has taken this a step further to develop a “cripistemology” of pain, restoring connections of pain to sociocultural contexts (Patsavas, 2014). Discussions of pain are also found in many other critiques of the social model however, in this theory, the normativity and even desirability of being pain-free is examined. Discussions of the significance of pain are very relevant to (and often come from those with chronic conditions). Pain sensation is highly medicalized and, as argued by Illich, this deprives the subjective experiences of suffering of cultural, social and personal meaning. In other words, medicalized pain is always seen as a problem; therefore, suffering is a problem that can best be fixed with medicine (Illich, 1976). For those with MS who experience pain as a symptom, this narrows the possibilities for pain and suffering to be personally meaningful in any positive sense.

Those who affirm a non-tragic experience of impairment and disability align with Swain and French’s “Affirmative Model of Disability.” This model is largely concerned with the identities that people ascribe to themselves, and that disability culture is evidence of disability as part of a collective, positive and desirable identity (Swain & French, 2000). It is difficult to find evidence of an acceptance of this understanding among those with chronic illness. Deaf culture is an oft-cited example of affirmation of a non-tragic experience with disability (Corker, 1996). This culture is vastly different than cultures surrounding chronic disease conditions where the culture is more of a support system-helping each other through our collective experience (of suffering) (Crooks, Chouinard, & Wilton, 2008).

More recent critiques of the strong social model include discussions on the importance of intersectionality, (i.e. that identities are not additive, they exist in complicated and multidimensional relationships) (McCall, 2005). For those in this camp (also emerging from feminist roots), the experiences of a black woman with MS and a white man with MS are vastly



different, and these differences lead to disablism in vastly different ways. Resistance theories have also emerged, emphasizing that what unites all of the offshoots of the social model is a resistance to oppression and disability (Gabel & Peters, 2004). In this theory, even utilizing medical care can be considered “resistance.” This theory seeks to account for those who do seek for cure, such as those with MS, whereas other theories table the issue of cure as it is highly contested among researchers and disability activists (Beauchamp-Pryor, 2011; Clare, 2017; Hahn & Belt, 2004; Kim, 2017).

Many others also critique the social model for its lack of focus on the body at all, calling for an increase in phenomenological research and an embodied ontology. These critics posed the question “where does impairment stop and disability end”? (Shakespeare & Watson, 2002) From these questions, Carol Thomas put forth what is now called the Social Relational Model of Disability. She subscribes to a “non-reductionist materialist ontology” and defines impairments as “those variations in the structure, function and workings of bodies which, in Western culture, are medically defined as significant abnormalities or pathologies...The body itself is a social product, as well as a physically changing ‘biological’ entity...” (Thomas, 1999) p. 8. She uses the term “impairment effects” to describe:

The direct and unavoidable impacts that ‘impairments’ (physical, sensory, intellectual, emotional) have on individuals’ embodied functioning in the social world. Impairments and impairment effects are always bio-social and culturally constructed in character, and may occur at any stage in the life course. (Thomas, 2012) p 211

These impairment effects interact with and are informed by social aspects of disability; not just structural limitations on what disabled people can *do* but on social limitations on who disabled people can *be* (Thomas, 2007). The term “psycho-emotional disablism” was put forth by Thomas and discussed further by Reeve to discuss “the psychological effects of exclusion, discrimination and prejudice” (Reeve, 2002) p. 493.

It is this social-relational understanding of disability which I argue to be most suitable to situate the experiences of individuals with MS because of its consideration of the interaction between biological and the social and the importance of the psychological impact of oppression. However, another loosely related perspective deserves mention. Many postmodernists have heavily critiqued the social model as well as other emerging models of disability. Shakespeare, a well-known critic of the strong social model said:

...disability is the quintessential post-modern concept, because it is so complex, so variable, so contingent, so situated. It sits at the intersection of biology and society and of agency and structure. Disability cannot be reduced to a singular identity; it is a multiplicity, a plurality. (Shakespeare & Watson, 2002, p. 19)

This intersection of biology and society and of agency and structure gives the Social Relational Model of Disability a degree of nuance that is suitable for framing a study with individuals with MS. Above, I have provided a description of MS in terms of disease, illness, and sickness. Much of the description of MS as a disease also describes the possibilities of impairment effects in this population and the discourses contributing to psycho-emotional disablism.

The strengths of the Social Relational Model of Disability are its provision for subjective experiences of pain, discomfort and loss of function as interacting with the social world. For example, Wendell has discussed that the mere “pace of life” is a significant part of what makes fatigue as a symptom of many chronic diseases, including MS, problematic. However, she believes that there is a physical difference between how she feels on days when she is fatigued and how she feels on days when she is not (Wendell, 1996, p. 37). It also acknowledges the role of society on both a structural *and* a psychological level as sources of oppression, whereas many other models emphasize only structural oppression and exclusion. The evidence that those with MS are greatly impacted by psychological oppression (both internal and external) as well as

structural inequalities supports the use of this model (Kralik et al., 2003; Mozo Dutton et al., 2012; Olsson et al., 2008).

To conclude this section, I wish to emphasize the centrality of liminality to the MS experience. The uncertainty about the disease/sickness/illness extends from its etiology to prognosis on an individual level and includes its place as a disability or an identity. While individuals with MS face a restructuring of self-hood and cope with these uncertainties, their place remains unclear; Can they claim disability? Do they want to? I now turn to questions of identity.

### **Disability Identity**

I will begin by outlining two different approaches to understanding disability identity; identity politics and psychosocial (self-concept) identity. Then I will outline the different models that have been put forth and the important constructs of each. I will then discuss the model which I will adopt for contextualizing my research and defend its usefulness for understanding disability identity among individuals with MS. Lastly, I will discuss how my preliminary research has indicated that exercise and physical activity may be implicated in the negotiation of an identity as disabled in the MS population.

**Disability Identity Politics.** For many Disability Studies theorists and scholars, disability identity is much more related to a group affiliation and this group's power to influence political action than the sense of self on an individual level. However, there is variation between these perspectives of the importance of the personal experience to the group identity. Many scholars use Dworkin and Dworkin's definition of minority identity as characterized by 4 qualities: identifiability, differential power, differential and pejorative treatment and group awareness (Dworkin & Dworkin, 1976). Tobin Siebers builds upon this framework adding a fifth category:

passing an ethical test, which is meant to ensure that radical fringe groups meeting the previous 4 requirements but that push for violent or oppressive agendas cannot argue for minority status. He also argues for the importance of disability identity politics that consider the personal experience of the individual as theoretically vital. He states:

...disability is not a pathological condition, only analyzable via individual psychology, but a social location complexly embodied. Identities, narratives, and experiences based on disability have the status of theory because they represent locations and forms of embodiment from which the dominant ideologies of society become visible and open to criticism...identity is, properly defined, an epistemological construction that contains a broad array of theories about navigating social environments...Thus identity is not the structure that creates a person's pristine individuality or inner essence but the structure by which that person identifies and becomes identified with a set of social narratives, ideas, myths, values and types of knowledge of varying reliability, usefulness and verifiability... (Siebers, 2008, pp. 14-15).

The disabled individual's experience as a marginalized person provides a means of critiquing the normative practices of mainstream society. Siebers' definition of disability identity emphasizes how a person's narratives and experiences illustrate the way they position themselves in society and the way society positions itself to him or her and those that are similar. Siebers' goal with his theory of disability identity is to "give disabled people greater knowledge of and control over their bodies in situations where increased knowledge and control are possible." Therefore, to adopt an identity as disabled is to accept the collective knowledge about managing the oppression of a society that devalues them and to join resistive efforts in personal and political ways. The benefits of adopting this identity are not just practical in nature but psychological.

Again, quoting Siebers:

In almost every case, however, people with disabilities have a better chance of future happiness and health if they accept their disability as a positive identity and benefit from the knowledge embodied in it. The value of people with disabilities to themselves does not lie in finding a way to return through medical intervention to a former physical perfection, since that perfection is a myth...Rather, embodiment seen complexly understands disability as an epistemology that rejects the temptation to value the body as

anything other than what it was and that embraces what the body has become and will become relative to the demands on it... p. 27

A political theory of disability identity can show the ways that we socially construct able-bodiedness as the norm (and the source of Siebers' temptation to return to a former physical perfection.) Indeed, Campbell defines ableism as "a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human" (Campbell, 2009, p.5). This definition adds depth to what is at stake without a political disability identity, that practices and discourses that reproduce a sense of diminished humanity associated with disability are left unchecked.

Similarly, Kafer argues for a political relational framework (Kafer, 2013) which recognizes the difficulty in categorizing individuals as disabled or not disabled; that there is no set of characteristics and definitions that would allow for easy classification. She sees disability "as a site of questions, rather than firm definitions" (p 11), which opens up the possibility of exploring differing orientations to identity and incorporating a wider range of embodied experiences in the collective identity of disability. Among her questions about the nature of disability and identity related to are "Do people with chronic illnesses fit under the rubric of disability?" and "What about people with some forms of multiple sclerosis who experience different temporary impairments-from vision loss to mobility difficulties-during each recurrence of the disease, but are without functional limitations once the MS moves back into remission?" (p.11). She recognizes that those with chronic illness, among many other groups, may or may not "fit" within traditional parameters of disability and impairment and thus cultivating a sense of identity around these terms can be potentially conflicting and problematic for many individuals. Rather than give clear cut definitions of the characteristics of those with impairments or who are

disabled, she uses Scott's term, "collective affinity" to describe that many can claim a part of disability identity and disability politics "not because of any essential similarities among them, but because all have been labeled as disabled or sick and have faced discrimination as a result." (p.11). Lastly, Kafer recognizes that many individuals might be identified by others as disabled (either from society at large or others who think critically about disability) but eschew this identity. She is careful not to assert that it would be better for them to adopt this identity but that regardless of their chosen identity, those individuals can benefit from a collective disability identity politics reimagining a future that is accessible for all.

There are two other important models of political disability identity relevant to this discussion. Hahn and Belt's "Minority group model of disability" emphasizes two important constructs: affirmation of disability identity and communal attachments (Hahn & Belt, 2004). Putnam's model emphasizes that important components of a political disability identity are: self-worth, common cause, pride, discrimination, policy alternatives, engagement in political action (Putnam, 2005). Three of these components are political in nature, while the other 3 are psychological in nature. Therefore, this model bridges the two approaches.

**Psycho-Social Identity.** For those who see a self-concept as an important and beneficial part of being human, developing a positive sense of disability identity is of particular interest. Recently, Forber-Pratt et al conducted a systematic review of literature concerning disability identity (Forber-Pratt et al., 2017). They identified 7 different models of disability identity development. Two were discussed above, Hahn and Belt, and Putnam, the others come from Gill, Gibson, Darling, Dunn and Burcaw, and lastly Forber-Pratt and Zape. Gill's constructs are centered around the developmental theme of integration. She describes four types of integration that are important for a sense of disability identity. They are: coming to feel we belong

(integration into society), coming home (integrating with the disability community), coming together (internally integrating our sameness and differentness), and coming out (integrating how we feel with how we present ourselves.) (Gill, 1994). Gibson puts forth a more stage-wise model, outlining the path that disabled individuals potentially take through accepting a self as disabled. They begin with passive awareness, move to realization, then to acceptance and finally identity (pride, but sometimes shame) (Gibson, 2006). This model more closely mirrors models of grief (Ahlström, 2007).

Darling conceptualizes a disability orientation continuum which includes cognitive and evaluative components of identity (I am a person with a disability vs. I am proud to be a person with a disability). Darling also includes adherence to a medical or social view of disability, as well as the degree to which one is involved with disability rights activism. These constructs compose a scale used to quantify disability orientation (Darling & Heckert, 2010). Dunn and Burcaw utilize a narrative model to understand disability identity. The constructs they have developed through their research in this area include: affirmation of disability, communal attachment, self-worth, pride, discrimination, personal meaning. These closely mimic Putnam's constructs; in fact, they utilize self-worth, pride and discrimination much the same way. However, they replace Putnam's political constructs with 3 other psychosocial constructs: affirmation of disability, communal attachment, and personal meaning (Dunn & Burcaw, 2013). Lastly, Forber-Pratt and Zape put forth their own "Model of Social and Psychosocial Disability Identity Development" that utilizes "statuses" to describe the degree to which a person affiliates with disability. These include: acceptance, relationship, adoption and engagement (Forber-Pratt & Zape, 2017).

All of the abovementioned models for understanding disability identity are used to understand how individuals with impairments navigate an identity as disabled and the political importance of that process. They have been applied in various ways with various populations.

### **Disability Identity and MS**

Kafer acknowledges that there are many individuals who do not currently identify as disabled because their impairments come and go, what Vick refers to as episodic disability. The abovementioned models do not adequately describe the experiences of these individuals, including individuals with MS.

There is some research into the experiences of those with episodic disabilities, those who “straddle the boundaries of sick and well, able and disabled” (Vick, 2013). Vick describes episodic disability as an in-between embodiment, meaning that individuals in this category do not inhabit a single identity as disabled or non-disabled. Rather, they can experience both able-bodiedness and disability as impairments fluctuate. Because individuals with MS sometimes may not feel that impairment/disability is a permanent part of themselves, this may impact the process of developing a disability identity. Indeed, Bogart argues that creating and fostering a disability identity for individuals with MS may be especially difficult considering the episodic nature of MS (particularly relapsing-remitting MS) (Bogart, 2015). The impairments experienced with MS may also complicate this process. Because the onset of MS is usually during early adulthood, individuals must face incompatibilities with a previous self-concept and may have a more difficult time developing a positive sense of identity related to disability than individuals with congenital disabilities (Bogart, 2014).

Mia Mingus’ concepts of descriptively and politically disabled are useful in understanding this aspect of MS. Mingus uses the terms “descriptively disabled” and “politically



disabled” to differentiate between individuals who may be identified as disabled and experience disability but who may or may not consider themselves as disabled.

When I say “descriptively disabled”, I mean someone who has the lived experience of being disabled. They may not talk about ableism, discrimination or even call themselves “disabled,” but they know what it feels like to use a wheelchair, experience chronic pain, have people stare at you, be institutionalized, walk with a brace, be isolated, etc. There are many people who are descriptively disabled who never become or identify as “politically disabled.” When I say “politically disabled,” I mean someone who is descriptively disabled and has a political understanding about that lived experience. I mean someone who has an analysis about ableism, power, privilege, who feels connected to and is in solidarity with other disabled people (regardless of whatever language you use). I mean someone who thinks of disability as a political identity/experience, grounded in their descriptive lived experience. (The same is true for descriptively queer, descriptively woman of color, descriptively adoptee and so on.) (Mingus, 2011).

Vick’s notion of episodic disability, and the in-between identity this entails, challenges static, binary understandings of what it means to be descriptively disabled. Individuals with MS live in liminal spaces between sick and well, able-bodied and disabled, and with an uncertain or ambiguous identity (and associated social expectations) for a variety of reasons. These individuals have a different, often ambiguous, sense of control over their descriptive disabled identity.

The salient point to reiterate is that individuals with episodic disabilities experience their bodies as indeterminate liquid borders that expand and contract within the material and discursive contexts in which they locate themselves. (Vick, 2013, p. 179)

Because of this, disabled identity in MS can be informed by notions of cure, management, and self-care behaviors that are grounded in social expectations of compulsory able-bodiedness. People with MS may feel a sense of responsibility to maintain a non-disabled identity/status because of their sense of control over MS (however ambiguous) or capacity for able-bodiedness through self-care behaviors aimed at minimizing or reversing impairment. Because the experience of MS is so often tied up in navigating the descriptive aspects of

disability (e.g. managing symptoms, passing), experiences with ableism and inaccessibility reinforce a sense of greater need for disciplining their own bodies rather than critiquing social structures that are disabling. This constrains the possibilities for taking up a sense of political disability identity for individuals with MS.

Therefore, understanding disability identity in this population necessarily involves consideration of the episodic, invisible, acquired, fluctuating, and often painful experiences of having MS, and how these influence the acceptance of descriptive disability status and the development of a political disabled identity.

## CHAPTER 2: THE MEDICALIZATION OF EXERCISE

“Exercise is Medicine” (EIM) has been a rallying cry for many kinesiologists, exercise scientists, physical therapists, personal trainers and others who assert that the very best thing a person can do for their health is to engage in exercise. This is exemplified with the words “Exercise is Medicine: A solution to one of the greatest public health problems of the 21<sup>st</sup> century,” emblazoned on the front page of their website (ACSM, 2017). What the greatest public health problem of the 21<sup>st</sup> century is, we are left to guess but likely they refer to a collection of chronic diseases including cardiovascular disease, diabetes and obesity.

Though well-meaning and by some thought to be a critique of western cultures’ reliance upon pharmaceuticals, EIM is the quintessential example of the medicalization of exercise, a phenomenon that comes with its own challenges and problems. I will start by defining medicalization and describing this process in exercise (though I will mostly be using the word exercise, I refer also to physical activity generally and in some instances fitness<sup>1</sup>). I will then describe the major critiques of the medicalization of exercise and what negative consequences are thought to occur with this type of exercise discourse. These I will relate to the chronic disease and especially the MS population. Lastly, I will provide a few examples of alternative exercise paradigms.

**Medicalization.** Zola famously put for the concept of medicalization to describe the changing role of medicine in contemporary society. His argument was that medicine:

...is becoming the new repository of truth, the place where absolute and often final judgments are made by supposedly morally neutral and objective experts. And these judgments are made, not in the name of virtue or legitimacy, but in the name of health...[this] insidious and often undramatic phenomenon is accomplished by

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<sup>1</sup> Fitness has a complex and unobjective history. Exercise is Medicine ‘fits’ within a long history of trends using exercise and physical activity to prepare citizens to be in ‘shape’ or ‘fit’ for service to their country. Exercise is Medicine shifts the focus from fitness for military service to fitness for productive service in the neoliberal, consumer society; reducing chronic disease increases longevity in the workforce. (McKenzie, 2013).

“medicalizing” much of daily living, by making medicine and the labels ‘healthy and ill’ relevant to an ever increasing part of human existence.” (Zola, 1972, p. 487).

Medicalization encompasses several important aspects of this changing process, including how ideas of illness and health are becoming increasingly relevant to daily activities of living (Verweij, 1999), how various social phenomena previously disconnected from the institution of medicine become linked to medicine (Crawford, 1980), how medicine is utilized as a means of social control (Conrad, 1992; Zola, 1972), epistemological issues where social and personal problems are seen in medical terms, using medical frameworks to understand them, and medicine “crowding out” other useful norms and metaphors (Garry, 2001; Wardrope, 2015), reinterpreting individuals as patients and creating markets designed for their participatory consumption (Clarke et al., 2003; Purdy, 2001), and increased concern with the prevention of disease and promotion of “health” (Crawford, 1980; Wheatley, 2005).

Preventive medicine and “surveillance medicine” have emerged as modern ideas that expand the medical gaze to include not only the clinic and hospital but all aspects of life (Verweij, 1999; Wheatley, 2005). As more parts of everyday life are now understood in terms of their capacity to make us sick, surveillance medicine dissolves the distinction between healthy and ill, and effectively seeks to bring “all forms of human conduct” (Wheatley, 2005) under its purview. Individual lifestyle behaviors are now a source of scrutiny and site of health-related discipline (Mayes, 2016).

In the context of surveillance medicine, the body is understood as an array of risk factors which, properly interpreted, can establish the probability of future illness. Disease is “identified in advance” of outward bodily symptoms, and this at-risk state establishes “infinite possibilities for the expansion of medical categories and interventions” (Wheatley, 2005, p. 202).

This phenomenon leads to additional emphasis of personal responsibility for health and blame for illness as individuals increasingly consider their behavior in terms of illness prevention (Verweij, 1999). Guttman and Salmon have critiqued the lack of ethical framework guiding current public health messages and interventions, particularly focusing on the ethics of messages on responsibility and culpability. They outline several ethical issues including: the implication of a causal link between behavior and health which in turn implies individual responsibility for negative health consequences, a societal attitude of victim blaming that de-emphasizes any other factors involved, creation of moral dichotomies between healthy/good citizens and unhealthy/bad citizens, financial penalties for those who engage in behaviors deemed to be ‘risky’, and reinforced self-blame, shame and helplessness (Guttman & Salmon, 2004).

**Medicalization of Exercise and Adverse ‘Side Effects’.** One increasingly common manifestation of surveillance medicine is the emphasis on exercise in relation to health and wellness (Pond, Stephens, & Alpass, 2010; Wheatley, 2005). Exercise, as evidenced by the EIM campaign, is becoming highly medicalized in the current health climate, and notions of virtue and moralizing exercise have been observed and critiqued (Guttman & Salmon, 2004; Wheatley, 2005). Though often the medicalization of exercise is thought to be associated with disease and health, it is also relevant to fitness and body shape, as “in popular culture, health ideals and physical beauty ideals have become congruent, as health has increasingly become inscribed on body shape” (Markula & Pringle, 2006) p. 81, (see also (Mayes, 2016)).

Markula and Silk further describe powerful motivations behind discourses contributing to the medicalization of exercise and fitness. They cite a report by the US Department of Health and Human Services stating, “A physically inactive population is at both medical and financial risk for many chronic disease and conditions.” (USDHHS, 2002). Therefore, “good and

virtuous” citizens are those who engage in exercise to avoid incurring financial burden for themselves, their families or their government.

With health and avoidance of illness as the seemingly preeminent motivations for the promotion of exercise in our current sociocultural climate, there comes a concomitant loss of meanings that exercise *could* have for many individuals as well as the possibility of a growing dissatisfaction with exercise because it cannot “do” what it is purported to do. This is especially relevant for those with chronic illnesses (including those with MS) and disabilities (B. Smith & Papathomas, 2014). The belief that exercise *is* medicine may prove to be problematic for individuals with chronic diseases that do not improve with exercise (or at least to a degree that individuals would find meaningful) or those who are disabled and excluded from participating in many exercise opportunities (due to structural or social barriers).

Increased blame, and stigmatizing attitudes towards disabled people (including those with chronic illnesses) – are dangers of a medicalized form of exercise. Furthermore, as Smith and Papathomas have argued, medicalized exercise reinforces the privatization of disability, emphasizes and underscores a medical model of disability (i.e. that disability is located within the individual; a result of individual pathology rather than a condition resulting in reduced access to participation in society because of mental or physical difference (Michael Oliver, 1983), instrumentalizes exercise and strips it of other possible values (e.g. enjoyment), and emphasizes the responsibility of the disabled individual to adapt and cope with difficult circumstances, not the broader social world (B. Smith & Papathomas, 2014). Reeve has explored the ways that medicalized self-care behaviors in general can simultaneously return ‘autonomy to the disabled person for care of the self...’ and be a source of scrutiny from non-disabled individuals (Reeve, 2002, p. 500). For example, for an individual with invisible symptoms resulting in impairment

and disability, self-care behaviors may not always be achievable, and these individuals may be judged and stigmatized for being ‘lazy’ or ‘irresponsible’ because there is no visible reason what they cannot engage in exercise. The consequences of these types of interactions, whether covert or overt, may impact the ways that self-care behaviors are taken up by individuals with a tenuous relationship with disability, especially for those who experience intermittent and unpredictable relapses of symptoms and disability. Feelings of responsibility and self-care agency that come with options for self-management can be at once empowering and disempowering in the face of the uncertainty of living with MS.

Medicalized exercise for individuals with chronic disease and disability ultimately reinforce an individual model of disability and reconnect disability with illness. Those targeted by these campaigns might become further estranged from mainstream disability rights movements and Disability Studies. Furthermore, the negative psychological outcomes as discussed in this section should not be ignored or treated as ‘side effects’ of exercise as medicine. I will now turn to the body of literature focused on exercise for multiple sclerosis; a population for whom exercise has the potential to become highly medicalized. With a clear understanding of the benefits of exercise as well as the negative outcomes of medicalizing exercise for those with MS, this section will frame the results of the current study in order to provide a respectful critique grounded in phenomenological experience with possibilities for moving forward.

### **Exercise and Multiple Sclerosis**

Among disability groups, MS is one of the most frequently targeted for exercise/physical activity (PA) interventions. According to a recent review of exercise interventions for disabled populations, there have been 54 studies conducted among persons with MS in the last 10 years.

By comparison, in persons with Parkinson's Disease, there have only been 10 (Lai, Young, Bickel, Motl, & Rimmer, 2017). There is also a plethora of cross-sectional and qualitative studies that explore the rates and correlates of PA and exercise among persons with MS, as well as their subjective experiences and perspectives on PA. In this section, I will first describe the rates of PA participation in this population, then I will describe the outcomes of interest for research on PA and exercise participation among adults with MS from quantitative and qualitative perspectives. Lastly, I will give an overview of the barriers and facilitators of PA participation for this population.

### **PA participation**

Previous research indicated that people with MS are less physically active than their counterparts without MS (Motl, McAuley, & Snook, 2005). With the increase in emphasis on PA promotion and PA research in this population as well as the advent of MS specific PA guidelines, we conducted an updated review in part to assess the impact of these more recent efforts. Adults with MS reported less PA participation than all comparison groups (both non-diseased and other clinical groups). However, when comparing non-diseased and clinical groups separately, the analysis indicated that those with MS are significantly less active than non-diseased populations but there exists only a small difference between MS and other clinical groups. We further separated the clinical groups into those with other chronic diseases (e.g. muscular dystrophy) and those with "healthy disabilities" (e.g. spinal cord injury, stroke), in other words, those who regard themselves as disabled but not sick). The PA participation levels of those with MS most closely resemble that of those with other chronic disease conditions. They are significantly less active than those with "healthy disabilities" and those considered non-diseased (Kinnett-Hopkins, Adamson, Rougeau, & Motl, 2017).



## **Physical Activity and Exercise Research**

Physical activity is an umbrella term under which is found exercise, leisure time activity, occupational activity, transportational activity, sports, housework etc. While targeted exercise interventions are common, there has been an increase of interventions aiming to increase lifestyle PA behavior in adults with MS. Lifestyle PA would include most physical activity that is not considered exercise. Several behavior change interventions targeting lifestyle PA have been conducted and yielded improvements in mobility, some measures of cognition, fatigue, depression, anxiety, pain and quality of life (Motl, 2014).

## **Exercise Interventions**

Exercise (defined as planned, structured, repeated physical activity done for the purpose of increasing or maintaining fitness) (Bouchard & Shephard, 1994), has been used in dozens of interventions among those with MS. There are several reviews of exercise studies conducted among individuals with MS that summarize the evidence regarding exercise's effects on MS disease activity, symptoms, and other measures such as quality of life (Motl & Sandroff, 2015). The strength of the evidence varies but overall suggests that exercise improves many of the physiological and psychological symptoms of MS (fatigue, balance, strength, depression, and related outcomes (quality of life) (Ensari, Motl, & Pilutti, 2014; Latimer-Cheung, Pilutti, et al., 2013; Motl, 2014a; Motl & Pilutti, 2012) and is associated with reduced occurrence of relapse and other positive neurological outcomes (Motl & Pilutti, 2016).

As a result of the summarization of these results, researchers have developed PA guidelines specifically for the MS population. They differ from ACSM guidelines in terms of total time per week of exercise. The MS PA guidelines recommend 2 days per week of 30 minutes of moderate intensity aerobic exercise and 2 days per week of resistance training to

include all major muscle groups (Latimer-Cheung, Martin Ginis, et al., 2013). These guidelines have the potential to be very beneficial on a practical level. Individuals with MS who are new to their altered embodiment might find comfort knowing what guidelines exist specifically for those in their situation. Indeed, previous qualitative research indicates that individuals with MS want MS-specific exercise information (Learmonth et al., 2017a, 2017b). However, they also have the potential to contribute to the more negative aspects of medicalized exercise. Guidelines, like dosage information, set a standard of behavior. Those operating below that standard might potentially be presumed to be non-compliant patients by healthcare providers or family members. Again, Reeve argues this can serve as a source of scrutiny that emphasizes the individual's responsibility over their impairment, rather than the social/structural/political responsibility for addressing disability (Reeve, 2002; B. Smith & Papathomas, 2014).

### **Qualitative Research on PA Role and Impact**

Researchers across epistemological traditions have conducted qualitative work that seeks to understand what people with MS perceive the role of exercise to be in their lives. Borkoles et al conducted an Interpretive Phenomenological Analysis (IPA) of 7 interviews with individuals with MS. They sought to understand the experiences of these individuals related to exercise, their experiences exercising before MS, how it changed, the barriers they faced to engage in exercise as well as their fears. The main themes that they described were a struggle to accept functional limitations to exercise, feelings of loss over not being able to exercise as they did before their MS symptoms began, and discomfort with the view/gaze of others when exercising.

Interestingly, they report that their participants use exercise as a means of gaining control *over* MS, a psychological benefit that cannot be measured in other ways (Borkoles, Nicholls, Bell, Butterly, & Polman, 2008). Kasser provides a description of motivations and meanings that

individuals with MS ascribe to exercise, namely that exercise becomes more of a necessity than a choice in order to maintain health and function. Furthermore, she outlined the perceived impact of participating in an exercise program as increased self-efficacy in a group context and improved hope and optimism (Kasser, 2009).

### **Overview of Impact**

Overall, from a physiological perspective, PA and exercise participation improve many of the symptoms of MS (Latimer-Cheung, Pilutti, et al., 2013; Motl & Sandroff, 2015), many of the underlying processes of the disease, and can reduce rates of relapse (Motl & Pilutti, 2016). From a psychological perspective, there is evidence for improvement of depression, anxiety, self-efficacy, well-being, self-control, vigor, and sense of accomplishment (Learmonth & Motl, 2015; Motl & Sandroff, 2015). Socially, participation in exercise and PA impacts family relationships, provides a context for forming new friendships, and increases participation in social activities (Learmonth & Motl, 2015).

### **Predictors and Correlates**

One study provides evidence that those who report greater enjoyment of exercise and higher level of exercise self-efficacy are more likely to engage in exercise ( Motl, Snook, McAuley, Scott, & Douglass, 2006). Another study looking further into social cognitive variables described an association between goal setting behavior and barriers with PA (i.e. increased scores on measures of goal-setting were associated with higher PA participation and higher scores on measures of PA barriers were associated with lower PA participation (Suh, Weikert, Dlugonski, Balantrapu, & Motl, 2011). Furthermore, another study demonstrated that older age, use of a cane, unemployment, and progressive forms of MS were correlated with lower levels of exercise (Motl, Snook, McAuley, Scott, & Hinkle, 2007).

## **Barriers and Facilitators**

A recent synthesis of qualitative studies provides an exhaustive list of common barriers and facilitators to exercise/PA participation among those with MS. The most commonly cited barriers included environmental barriers (e.g. lack of accessible facilities, inappropriate exercise modalities, transportation, inappropriate temperature/climate, lack of opportunities, and a need for personalized program), social barriers (e.g. conflicting or lack of information from healthcare professionals, social exclusion, dependence on others, family responsibilities, social stress and stigma), personal health barriers (e.g. fatigue, fluctuation of symptoms, lack of personal knowledge, pain, symptom progression, medication side effects, and other musculoskeletal problems), and other personal barriers (e.g. fear, lack of self-management, loss of self-control, frustration with limitations, apathy towards independent exercise, depression, dislike of exercise, low illness acceptance, and forgetfulness.) (Learmonth & Motl, 2016)

The most commonly cited facilitators included environmental (e.g. related to positive characteristics of the exercise itself, accessible venues, transportation availability, MS role models, peer support, coaches knowledgeable in MS, social accountability, supportive family and coaches), and personal (e.g. appropriate exercise program for personal capabilities, resting, sense of accomplishment, awareness of improvement, autonomy in exercise, and learning coping strategies.) (Learmonth & Motl, 2016).

The research in this area indicates that individuals with MS are experiencing structural disability in the form of inaccessibility even if they are not identifying as disabled. Importantly, since structural barriers are among the most commonly cited inhibitors of PA in this population (and likewise accessible PA opportunities one of the greatest facilitators), the relevance of adopting a disabled identity is relevant to all concerned with PA participation in this population.

## **Alternative paradigms**

To deny that individuals could glean benefits relevant to their health through exercise would be a naïve approach to shifting paradigms in exercise promotion. However, if the only motivations to participate are to gain health benefits and reduce impairment/disability, then exercise will lose the possibilities for other meanings, and could inhibit the process of adopting an identity as disabled. The negative psychological outcomes of guilt and shame as well as the psycho-emotionally disabling stigma of non-participation can be addressed by shifting paradigms without losing the possibilities of improved quality of life with participation. A secondary aim of this dissertation is to conceptualize an alternative paradigm of exercise promotion for the MS population that acknowledges the benefits of exercise while resists the negative aspects of our current promotion practices. Two concepts will frame this endeavor in combination with the results of this study.

**Empowerment.** Theories of behavior change have been utilized as means of targeting health-related behaviors and either increasing them or decreasing them in theoretically sound ways. An alternative to behavior change models is empowerment. Empowerment is classified both as a process (someone is empowered to do something) and as a state or goal; “to be empowered is to have control over the determinants of one’s quality of life” (Tengland, 2016) p. 34. The emphasis upon quality of life, rather than health is an important distinction. While health can be an important component of quality of life (as in Health Related Quality of Life), it is not a requisite component. Therefore, among those who experience chronic illness, exercise can contribute to improving quality of life without necessarily improving a subjective or objective state of health. There is evidence that improvements in quality of life with participation in PA through pathways of social support and self-efficacy, not only through pathways of specific

symptoms (Motl & McAuley, 2009). The benefits of using an empowerment model for discussing exercise are that it lacks a paternalistic quality evident in medicalized exercise promotion efforts, it avoids victim-blaming, and avoids stigmatization by underscoring larger social and structural forces at play, not just the individual's role in his or her life (Tengland, 2016).

**Technologies of the self and practices of freedom.** Foucault described ways of constructing identities not subjected to control of other entities or discourses. He defined these *technologies of the self* as means to:

Permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality. (Foucault, 1988) p. 18.

Markula has extensively written on the relevance of Foucault and the technologies of the self to exercise and fitness in modernity (Markula, 2004, 2014; Markula & Chikinda, 2016; Markula & Pringle, 2006). She emphasizes repeatedly that certain activities (exercise) are not inherently acting as practices of freedom—the transformative use of those activities comes with critical thinking, problematization of the identities related to engaging in exercise and the creative reimagination of self (Markula & Pringle, 2006). Some of the benefits of incorporating principles discussed here include a reimagination of the value that exercise can have for an individual with a marginalized identity, and the possibility for that value to empower disabled individuals to resist mainstream views of disability.

## CHAPTER 3: MS, EXERCISE AND DISABILITY IDENTITY

### Note to the reader

This chapter is comprised of a previously published research paper which led to the development of the current dissertation project. Its place in this dissertation is vital as the themes discussed in this paper were the precursors to the proposed dissertation research. The copyright owner has provided permission to reprint.

Adamson, B. C., Adamson, M. D., Littlefield, M. M., & Motl, R. W. (2018). 'Move it or lose it': Perceptions of the impact of physical activity on multiple sclerosis symptoms, relapse and disability identity. *Qualitative Research in Sport, Exercise and Health*, 10(4) 457-475.

### Abstract

This study explores the roles which individuals with multiple sclerosis (MS) ascribe to physical activity (PA). PA is becoming more heavily promoted by healthcare providers to individuals with MS due to the evidence of improved health outcomes with PA participation. However, there are possible negative outcomes with the medicalization of PA (e.g. increased guilt over inactivity, constrained views of PA) that may be compounded by the uncertain nature of having MS and negotiating a disabled identity. Framing disability and impairment within a social-relational model of disability, we undertook an interpretative phenomenological analysis (IPA) of 15 semi-structured interviews conducted among adults with MS who had recently experienced a relapse. Our purpose was to understand how persons with MS describe the roles of PA and exercise as part of daily life with MS, relapses, and disability identity. Our analysis indicated that PA occupies several roles related to MS and relapse. These roles were categorized into three main themes: PA has a paradoxical role in MS relapse; PA has a role in guilt and empowerment; and PA as defiance of disability. The roles that exercise/PA take may inform the negotiation of disability identity for individuals with MS by providing ambiguous control “over”

MS relapses and over impairment/disability. When not engaging in PA, our participants described feelings of guilt, worrying that increased impairment/disability would be their “fault.” Because of this, PA should be promoted carefully as it occupies many important and sometimes conflicting roles in the life of an individual with MS.

## **Introduction**

Multiple sclerosis (MS) is a neurological disease of the central nervous system (CNS) with an approximate prevalence of 2.5 million people worldwide (National Multiple Sclerosis Society, 2005b). This disease results in a wide-range of consequences including loss of mobility, muscle spasms, weakness, sensory deficits, fatigue, sexual dysfunction, cognitive disturbances and mood disturbances (Compston & Coles, 2008). MS is typically episodic in nature where relapsing-remitting MS (RRMS) involves periods of relatively stable symptomology interspersed with relapses that are characterized by acute disease activity (i.e., inflammation) and increased functional and symptomatic burden (Vollmer, 2007). That is, individuals with MS experience ongoing and unpredictable changes in impairments over the course of this disease brought on by acute inflammation, despite medical management (though not all individuals with MS choose to use medical therapies (Apel, Greim, & Zettl, 2005)).

Within the medical community, those with MS are considered to have a ‘disabling disease’ (Kurtzke, 1983). This reflects a medical model approach to disability wherein disability is located within the individual and is the result of individual pathology rather than a condition of reduced access to participation in society because of mental or physical difference (Oliver et al., 2006). This is in contrast with current social models of disability for discussing chronic disease associated with disability. Nevertheless, critiques of strictly medical and strictly social models of



disability have resulted in the development of new models that account for the experience of those with chronic conditions/diseases (Thomas, 2012; Wendell, 2001). According to the social-relational model of disability, disability is a result of the complex interplay of restriction of activity, impairment effects and psycho-emotional disablism. Restrictions on participation in society stem from the lack of accommodations for meeting the needs of those with impairments. Impairment effects are the ‘restrictions on bodily activity and behavior that are *directly attributable* to bodily variations’(Thomas 2007, p. 136), and psycho-emotional disablism is defined as ‘the psychological effects of exclusion, discrimination and prejudice’ (Thomas 2007; Reeve 2002, p. 493). This model has been used in research with other chronic conditions (for example Ferrie & Watson, 2015; Simpson, McMillan, & Reeve, 2013). This social-relational position underscores the importance of understanding the perspectives held by individuals with MS regarding symptoms, disability, and health behaviors before complementary MS management options are heavily promoted.

There is some research into the experiences of those with episodic disabilities (such as those with RRMS) who ‘straddle’ the boundaries of sick and well, able and disabled (Vick 2013, p. 178). Vick describes episodic disability as an in-between embodiment, meaning that individuals in this category do not inhabit a single identity as disabled or non-disabled. Rather, they can experience both able-bodiedness and disability as impairments fluctuate. Because individuals with MS sometimes may not feel that impairment/disability is a permanent part of themselves, this may impact the process of developing a disability identity (a positive self-concept of oneself as disabled) (Dunn & Burcaw, 2013; C. J. Gill, 1997). Theories and models of disability identity are generally political or psycho-social in nature, though several acknowledge the importance of both understandings of identity (Forber-Pratt et al., 2017; Putnam, 2005;

Siebers, 2008). Theories of disability identity that are more political in nature concern themselves much with disability affirmation, critique of compulsory able-bodiedness, communal attachment and engagement in political action (Hahn & Belt, 2004; Kafer, 2013; Putnam, 2005; Siebers, 2008). Psychosocial theories and models emphasize self-worth, integration of conceptions of self, personal meaning, and include models which map disability identity development as a stage-wise process (Gill 1994; Gibson 2006; Darling & Heckert 2010; Dunn & Burcaw 2013; Forber-Pratt & Zape 2017).

Bogart argues that creating and fostering a disability identity for individuals with MS may be especially difficult considering the episodic nature of MS (particularly RRMS) (Bogart, 2015). Because the onset of MS is usually during early adulthood, individuals must face incompatibilities with a previous self-concept and may have a more difficult time developing a positive sense of identity related to disability than individuals with congenital disabilities (Bogart, 2014). Previous phenomenological research among those with MS (and those with other chronic illnesses, (Charmaz, 1983)) illustrates that the diagnosis of MS challenges a person's sense of identity, leading to the need for a new conceptualization. The restructuring is often marked by a sense of loss (Ahlström, 2007; Mozo Dutton et al., 2012; Werner, Isaksen, & Malterud, 2004), liminality (Strickland, Worth, & Kennedy, 2017), fear of stigma associated with invisible (and often discredited) impairments (Grytten & Måseide, 2005), uncertainty (Strickland et al., 2017), sorrow and vulnerability (Isaksson & Ahlström, 2008). Furthermore, because MS is classified as a neurological *disease*, it is therefore tethered to the medical realm, where there is the hope of managing the distressing symptoms and slowing progression of the underlying disease (C. Donze, 2007; Cecile Donze, 2015). Individuals with MS may assume an

active role in treating their MS to prevent or remove symptoms or avoid disability. Perhaps the clearest example of this is with physical exercise.

Recent years have seen a surge in research on the benefits of exercise for symptoms of MS (Lai et al., 2017). There are several reviews of exercise studies conducted among individuals with MS that summarize the evidence regarding the effects of exercise on MS disease activity, symptoms, and other measures such as quality of life (Robert W. Motl & Sandroff, 2015). The overall evidence suggests that exercise improves many of the symptoms of MS (fatigue, balance, strength, depression) and related outcomes (quality of life) (Ensari et al., 2014; Latimer-Cheung, Martin Ginis, et al., 2013), and is associated with reduced occurrence of relapse and other positive neurological outcomes (R. Motl & Pilutti, 2016).

The evidence is compelling that exercise leads to improved health outcomes for MS, and thus the emphasis of health benefits underscores promotion efforts, research agendas and possibly individual motivations for engagement in exercise. This is exemplified in other populations with chronic conditions by the ‘Exercise is Medicine’ campaign. This campaign seeks to further medicalize exercise by encouraging healthcare professionals to ‘prescribe’ exercise or treat physical activity participation (or inactivity) as a vital sign (ACSM, 2017). Exercise promotion therefore has the potential to become highly medicalized in the MS population and seems to currently emphasize avoidance of future disability. For instance: ‘The role of exercise and physical activity may be even more important in a population facing functional deterioration...But exercise is not effective if people will not do it’(Mayo et al. 2013, p. 2). Similarly, the National MS Society (NMSS) highlights the importance of exercise on their website: ‘In addition to being essential to general health and well-being, exercise is helpful in managing many MS symptoms’(NMSS 2017, para. 1). However, if exercise promotion

discourses emphasize that exercise will prevent ‘functional deterioration,’ they likewise imply that inactivity will hasten functional deterioration. There is a robust field of research dedicated to the study of inactivity (not meeting physical activity guidelines) and sedentary behavior (high levels of sitting) which promote this belief in the general population (Tremblay et al. 2010; Owen et al. 2009).

Critics of ‘risk discourse’ (e.g. inactivity as a risk for functional deterioration) and surveillance medicine highlight the ethical problems with messages and promotional efforts emphasizing personal responsibility and culpability (Bayer, 2008; Crawford, 1977; Verweij, 1999; Wheatley, 2005). Personal responsibility is a foundational tenet of medical/individual models of disability as well as current health behavior paradigms. These ethical issues include the implication of a causal link between behavior and health (which in turn implies individual responsibility for negative health consequences), a societal attitude of victim blaming that de-emphasizes any other factors involved, creation of moral dichotomies between healthy/good citizens and unhealthy/bad citizens, financial penalties for those who engage in behaviors deemed to be ‘risky,’ reinforced self-blame, shame and helplessness, and the resulting absolution of social and political agendas of the need to address health concerns on a population level (Crawford, 1977; Foucault, 1963; Guttman & Salmon, 2004; Ingham, 1985; Wheatley, 2005).

Given the ways that discourses circulate, it is quite possible that this cause and effect hypothesis has spread beyond the medical community, even among individuals with MS. This belief may prove to be problematic for individuals with MS who experience varying degrees of uncertainty related to having MS. Furthermore, given the individualistic nature of exercise promotion (Wheatley, 2005) as well as the still widely accepted medical model of disability

(Oliver 2013), the exercising individual with MS may still develop severe impairments and then would be left to sort out what went wrong and how he or she was at fault, rather than how society has oppressed, invalidated or marginalized his or her experience. This may also impact the ways that individuals with MS perceive exercise and physical activity options (Borkoles et al., 2008), their own evaluations of their exercise and physical activity behaviors (Pond et al., 2010) and the relationship between exercise and disability identity.

These outcomes – increased blame, and stigmatizing attitudes towards disabled people (including those with chronic illnesses) – are dangers of a medicalized form of exercise. Furthermore, as Smith and Papathomas (2014) have argued, medicalized exercise reinforces the privatization of disability, emphasizes and underscores a medical model of disability, instrumentalists exercise and strips it of its intrinsic value (e.g. enjoyment), and emphasizes the responsibility of the disabled individual to adapt and cope with difficult circumstances, not the broader social world (B. Smith & Papathomas, 2014).

Reeve has explored the ways that self-care behaviors in general can simultaneously return ‘autonomy to the disabled person for care of the self...’ (Reeve 2002, p. 500), and be a source of scrutiny from non-disabled individuals (Reeve, 2002, 2006). For example, for an individual with invisible symptoms resulting in impairment and disability, self-care behaviors may not always be achievable, and these individuals may be judged and stigmatized for being ‘lazy’ or ‘irresponsible.’ This along with myriad other examples Thomas terms psycho-emotional disablism (Thomas, 2007). The consequences of these types of interactions, whether covert or overt, may impact the ways that self-care behaviors are taken up by individuals with a tenuous relationship with disability, especially for those who experience intermittent and unpredictable relapses of symptoms and disability. The impact of self-care behaviors, such as exercise, on creating and

embracing a positive disability identity have not been explored among adults with MS, and thus, before exercise and PA are widely promoted as a means of self-care to individuals with MS, it is important to gain a better understanding of the ways that exercise and PA are taken up by this population.

## **Purpose**

This study sought to understand the ways that individuals with MS who had recently experienced a relapse describe the roles of PA/exercise regarding MS itself, relapses, and disability identity. By roles, we specifically mean the attributed function of PA relative to any given situation or outcome. We chose the MS relapse as a unique time-point in the experience of the individual with MS. It is a period of increased symptomology. MS relapses often require medical management or at least interaction with healthcare providers. This time-point may be inordinately laden with self-blame, criticism and introspection in relation to disability and self-care behaviors (Asano, Duquette, Andersen, Lapierre, & Mayo, 2013; Kalb, 2007). To gain a clearer understanding of the ways that self-care behaviors such as PA are understood, it is vital to foreground the perspectives of individuals with MS who have recently experienced a relapse. Furthermore, as our primary research goal was to gain an understanding of the meanings that individuals attribute to exercise in regards to MS, disability, and identity, Interpretative Phenomenological Analysis (IPA)'s emphasis upon complexity, process or novelty (Smith & Osborn 2003, p. 53) provided the best approach. It has previously been particularly useful for producing sensitive and nuanced descriptions of experiencing disability (Borkoles et al., 2008; Irvine et al., 2009), loss of identity (Mozo Dutton et al., 2012), and shame related to physical activity (Borkoles et al., 2008) among those with MS; all of which are themes we expected to

encounter in the current study. IPA seeks to answer the question *'how are participants making sense of their personal and social world?'* (Smith & Osborn 2003, p. 51). IPA's use in studies of individuals with MS as well as sport and exercise studies is documented (Borkoles et al., 2008; Irvine et al., 2009; Mozo Dutton et al., 2012; Pridgeon & Grogan, 2012).

## **Methods**

### **Research Paradigm**

This research study is underpinned by a non-reductionist materialist ontology (Thomas, 1999, 2007)) that acknowledges the complex bio-social nature of embodiment, and a subjectivist epistemology (interactive researcher/participant knowledge-making process) (Markula & Silk, 2011; p. 31). The social-relational model of disability provides a framework for understanding that the experience of the individual is a function of his or her embodiment (including impairment), the social and political landscape of his or her world (that society oppresses, has certain ideals and expectations surrounding illness, and this includes history, language and power relations (Markula & Pringle, 2006)), and the psychological impact of oppression, stigma, prejudice and discrimination (Reeve, 2002; Thomas, 2007).

### **Participants and Recruitment**

Consistent with IPA recommendations, we purposefully sought to recruit a homogenous cohort of participants. IPA emphasizes the importance of a small, homogeneous sample of participants in order to gain a detailed understanding of a phenomenon of interest (JA Smith & Osborn, 2003). We contacted participants who had previously participated in research within our laboratory via e-mail. We further advertised at local MS events (e.g. research symposia, MS

Walks and fundraisers). We screened those who were interested over the phone based on the following inclusion criteria: a) age 18 years or older, b) confirmed diagnosis of MS, c) occurrence of a relapse within the past 6 months, but not within the past 1 month, d) Patient-Determined Disease Steps (PDDS) score of  $\leq 6$  (this scale determines degree of impairment experienced by persons with MS), and e) willingness to be audio-recorded during the interviews. The qualitative methodology was approved by the University of Illinois Institutional Review Board and we obtained written consent from all participants before data collection. Participant information can be found in Table 1.

## **Procedure**

**Data Collection.** Participants were given the option to come to the University of Illinois lab space to complete the project or to choose a public space close to their homes (e.g. library study rooms). Regardless of the option chosen, all data collection procedures were conducted in a quiet, private room. We first conducted a brief neurological exam, i.e. the Expanded Disability Status Scale (conducted by BCA). This commonly used metric for understanding and quantifying MS impairments involves the rating of impairments and impact on function in 7 neurological areas (including vision, sensation, mobility, bowel and bladder function, etc.) (Kurtzke, 1983)). Commonly-used cut-offs for delineating mild, moderate and severe impairments are 0-3.5 (mild), 4-6.5 (moderate), and 7-10 (severe). We further administered a demographic questionnaire and the Godin Leisure-Time Exercise Questionnaire (GLTEQ)(Godin, 2011).

Semi-structured interviews lasting approximately 1 hour were conducted by authors BCA or MDA. Both interviewers have experience conducting semi-structured interviews among adults



with MS and other ‘clinical’ populations. Semi-structured interviews are consistent with an IPA approach as they allow for a stage of rapport-building, ability to probe, and ability to follow the participants’ interests. This allows for richer data to be collected. The interview guide was developed by authors BCA, MDA and RWM according to IPA guidelines (JA Smith & Osborn, 2003). First, the topics to be discussed were determined. These included the impact of MS relapse on PA behavior, the concerns about PA post-relapse, and the needs of the individual. Second, topics were ordered in a way that would allow participant and interviewer to establish rapport and leave sensitive topics (such as their uncertainty about disability) for the latter portion of the interview. Third, questions and probes were carefully crafted to avoid leading, and biased answers. Interviewers BCA and MDA practiced using the interview guide and made changes as needed before beginning the recruitment process. The interviews generally began with questions concerning the meaning of PA and exercise to the participant. We then asked about perceptions of PA as part of MS care, PA/exercise routines, recent relapse(s), the impact of that relapse on PA and exercise and access to exercise/PA resources. The interview schedule can be found in Appendix A.

**Analysis.** We analyzed the interviews following IPA guidelines with the intent to understand the participants’ sense-making (Smith & Osborn 2003; Brocki & Wearden 2006, p. 88) of the varied roles of PA/exercise. Interviews were transcribed verbatim, then interpreted line-by-line by authors BCA and MDA. Interview transcripts were read through, audio-recordings were listened to, and notes relevant to the ascribed roles of PA were made initially on the transcripts. After the initial read-through of a transcript, the interview and notes were read again. Authors determined broad themes and met to discuss examples, as well as the participant and researcher

interpretations of those themes within a single interview. Furthermore, lists of converging and diverging interpretations within these themes were kept within the overall list of themes and definitions. The themes were then ordered under superordinate theme categories. Authors BCA and MDA continued this process for each interview and compared the overall list of themes to previously analyzed interviews, meeting to discuss the interviews, themes and interpretations. This process involved continuously referring back to the transcripts. Similar themes described differently by the two researchers were discussed and renamed if needed. We created a master list of themes (e.g. guilt, enjoyment, treatment of MS), including interpretations, that were categorized into superordinate themes (e.g. role in MS care, disability identity, empowerment). This list contained exemplary quotes from participants as well as diverging quotes. At this stage, the results were described, and a literature search of the superordinate theme categories was conducted to provide contextualization of our results. All researchers then discussed the relationship of the different roles of PA and exercise, how these themes related to each other, and connected the themes to wider discourses regarding disability (identity), medicalization of exercise and self-care.

**Quality.** Smith (J Smith, Flowers, & Larkin, 2009; JA Smith & Osborn, 2003) outlines two important criteria for determining credibility within IPA studies. First, arguments generated should be internally consistent and supported by data gathered, and second, it is important to provide sufficient excerpts to allow readers to evaluate the interpretations provided by the researchers. Therefore, we have sought to include exemplary excerpts from our participants that highlight the variety of experiences and perceptions. These criteria were appropriate given our subjective epistemology and were supported by aspects of more recent frameworks (e.g. thick description and multivocality as components of credibility) (Tracy, 2010) and critiques of rigor

in qualitative research in the context of sport and exercise (B. Smith & McGannon, 2017). Smith and McGannon highlight the importance of criteria and methods for ensuring rigor that are consistent with epistemological and methodological underpinnings of the research study and avoid problematic use of commonly-used methods of establishing rigor. Lastly, upon receipt of reviews for the manuscript, authors returned to the interview data before making changes to ensure that changes made were consistent with our data.

### **Results and Discussion**

Fifteen individuals participated in the research study. We analyzed 15 interviews and gathered information on level of impairment, current level of exercise participation, and basic demographic information as background to contextualize interview data. This information is provided in Table 1. We present results from the three superordinate themes of the current analysis, i.e. PA has a paradoxical role in MS relapse, PA has a role in guilt and empowerment, and PA as defiance of disability and include discussion of these themes throughout. Each participant quote is accompanied by a description of the level of impairment (as measured by the EDSS) and exercise participation level (as measured by the GLTEQ).

**Table 1. Participant Demographic Information**

Participant Pseudonym	Gender	Age	Employed (Y/N)	Race/Ethnicity	EDSS score*	GLTEQ score**
Elizabeth	F	57	N	White	5.0	6
Maria	F	61	N	Latina	6.5	30
Amanda	F	36	Y	White	3.5	18
Natalie	F	30	Y	White	3.0	36
Shawna	F	70	Y	American Indian	2.5	8
Leslie	F	42	Y	White	3.5	3
Tammy	F	41	Y	White	6.0	0
Patricia	F	64	N	White	6.0	11
Carrie	F	48	Y	White	3.5	21
Jen	F	49	N	White	5.5	9
Kayla	F	33	Y	Black	6.0	64
Sam	M	44	N	White	5.5	22
Bonnie	F	63	N	American Indian	5.5	21
Larisa	F	27	Y	Latina	3.0	21
Rebecca	F	58	N	White	5.5	41

\*EDSS=Expanded Disability Status Scale. Minimal level of impairment=0-3.5, moderate level of impairment=4.0-6.0, high level of impairment= 6.5+. (Kurtzke, 1983)

\*\*GLTEQ=Godin Leisure Time Exercise Questionnaire. Low level of exercise participation=0-13, moderate level of exercise participation= 14-23, high level of exercise participation=24+. (Godin, 2011)

**MS relapse.** Many individuals discussed using PA or exercise as a way to prevent future relapses. Some individuals engaged in exercise with the belief that this would prevent future relapses from occurring, ('I believe that if I keep up with my PA at home, which is not easy to be disciplined like I once was, but I believe if I do, it may be longer before the next relapse,' Tammy, (moderate impairment, low PA)). However, others discussed actively preparing themselves (and their bodies) to experience future relapses, in essence believing that if their bodies were physically fit, the relapses would not affect them as badly (i.e., a physiological reserve):

I think that the main thing with exercise is like if it's going to happen (a relapse) that's out of your control. You can't determine that but you can control how physically fit... so I think the best thing is to be as physically fit as you could possibly be in case it could happen again. Patricia (moderate impairment, low PA).

The participant here interestingly frames this discussion using the word control. She balances her lack of control over relapses (and perhaps by proxy MS itself) with a control over the fitness of her body, something she believes that she does have control over.

This loss of control over the body (or some aspects of the body) has been previously explored in the MS population as well as other chronic disease populations. Those with MS have discussed a loss of trust in the dependability of their bodies (Mozo Dutton et al., 2012) and this contributes to a self-body dualism (i.e. that unpleasant or painful parts of the body are placed outside the concept of the 'self')(Osborn & Smith 2006, p. 219). Our participants refer to exercise as a way to re-establish dependability of their bodies in some form.

Others discussed that by not exercising, they had brought on symptoms of a relapse thereby asserting their beliefs that exercising prevents symptoms/relapses from occurring. It was rare that individuals discussed the source of this belief as being outside of them (such as from a healthcare professional). Most often they cited personal experience as the reason for this belief, though the following quote demonstrates reaching for validation from others to affirm these beliefs.

I think I was the first one to like pin point (the source of the relapse), because I am really the only one that knows that I actually stopped exercising and eating right.... But definitely once I came up with 'I think this is what happened' other people, like my fiancé, were like "probably" and yeah. Larisa (low impairment, low PA)

These anecdotes were often related to relapses they had experienced in the past, not always necessarily the most recent.

A clear need for a balance between not exercising enough and exercising too much was expressed by individuals who believed that exercise had possibly exacerbated their MS symptoms or brought about relapses. Many discussed a need to ‘listen to my body’ in order to know how far to push to improve their symptoms without pushing too hard so as to avoid exacerbating symptoms.

It's like being on a tight rope, because you want to push yourself to get better and to get stronger. At the same time, you really have to pay attention to your body. If it's too much, then you need to stop. That was something that actually happened to me during my first attack. I was 21 years old, a junior. I was just getting ready to transfer to a university. I was 10 feet tall and bulletproof. I had this bad attack. I started getting better, but I forced myself to walk a mile to my class. Instead of taking the elevator, I'd take all the stairs upwards. I'm just sweating like I just ran a marathon. I thought I was doing good for myself, but I ended up actually having another attack. I've learned that you want to push yourself and do everything you can, but at the same time, if you think you're getting close to that danger line, you just have to stop and back up. Sam (moderate impairment, low PA)

Personal experiences clearly influenced Sam’s understanding of the balance of not enough and not too much exercise rather than medical advice. His experience pointed out a contradiction in his previous understanding of the benefits of exercise, i.e. ‘I thought I was doing good for myself.’ In this sense, persons with MS regain authority over their actions by using the language of ‘listen to my body’ and to some extent reject commonly accepted understandings about what is good for them. In this way, PA serves as a practice of freedom, allowing individuals to ascertain what is appropriate for them (Markula, 2004). Of note, several researchers have provided evidence that higher intensities of exercise actually do exacerbate some MS symptoms (Davis, Wilson, White, & Frohman, 2010), but there is other evidence disputing this phenomenon (Sandroff, Motl, & Davis, 2016).

Robert Crawford explores the ways health is seen as a social practice and points out an unsettling contradiction:

Some individual actions undertaken to improve health, including behavior changes requiring considerable effort or expenditure, turn out to be largely ineffective or even harmful. The alarm raised about the condition to be prevented remains while the pathway to increased protection becomes uncertain. (Crawford 2006, p. 416)

MS relapse and disability as the conditions to be prevented, and exercise as the pathway to increased protection is a poignant example of the contradiction Crawford is illustrating. Exercise, the very activity that could be preventive, is sometimes perceived to be harmful (e.g. ‘I thought I was doing good for myself but I ended up actually having another attack’). More paradoxical is the possibility that individuals with MS could engage in exercise to prevent impairment, but still develop impairment and then become faced with their own ‘failure’ to prevent a condition they thought they could control. Indeed, the experience of a relapse is often marked by blame and seeking for an explanation for its occurrence. The explanation often reflects back on the individual and what they did or did not do to ‘deserve this’ (Kalb, 2007).

**MS care and general health.** Every participant referred to exercise or PA as a form of treatment for symptoms of MS generally, not just for relapses. The belief that exercise and PA would either prevent or minimize future symptoms or reduce current symptoms was nearly universal. Most also mentioned the need to engage in PA for their health generally (not only related to having MS). It was unclear in some instances the source of this connection but often individuals described personal experiences that illustrated their beliefs in the effectiveness of PA for treating their symptoms. ‘I feel overall I've kept my strength up because I haven't just sat still and not done anything.’ Amanda (low impairment, moderate PA).

Several participants explained that they simply feel better on a daily basis when engaging in exercise, and this provides motivation. ‘Staying active and being mobile, I feel better than not being active and that’s the reason I do yoga four days a week.’ Shawna (low impairment, low

PA). Of note, though Shawna scored low on the GLTEQ, she here notes that she does yoga four days per week. Her perceptions of what exercise is and what she does are likely impacting her understanding of PAs role in her MS care. Others were quite ‘matter of fact’ about the need to be active.

Or it's easier for me to not do something. It's the wrong action because, for me, I actually get stiffer by doing nothing. I want to do something. My body wants to do something. For me, it doesn't really matter what it is, it's just do something. Get up and do something. Jen (moderate impairment, low PA).

Previous qualitative research conducted among adults with MS has revealed that individuals with MS perceive exercise to be an important part of their healthcare (Kasser, 2009; Learmonth et al., 2016). Kasser highlights that motivations often shift from being recreational in nature to being focused on health and functional outcomes with an MS diagnosis. Our interviews confirm this shift, namely that exercise and PA are highly related with health outcomes and that engagement in exercise and PA are forms of self-care.

## **Theme 2: PA has a role in guilt and empowerment**

The second theme encompassed much of the interpretation given by individuals about their own engagement in exercise. They described guilt in subtle ways and also described a sense of invigoration that accompanied participation in PA. We will describe first the ways that individuals described feelings of guilt followed by the ways PA contributed to a sense of empowerment.

**Guilt.** The expectations for engaging in PA behavior impacted the individuals’ response to their own efforts to be active. Phrases such as ‘I should be doing more,’ or ‘I need to get back into it’



were very commonly expressed. Such phrases hint at feelings of guilt over not engaging in what they believed was sufficient exercise or PA for their health needs.

I have a little routine that I try and do at least a couple of times a week. The stretchy bands and then pushups, sit-ups, leg lifts and that's my little exercise routine. It's not a big thing and I don't do it nearly long enough as I should but it hits all of the exercise points that I think are beneficial to me. Real exercise comes when I have to ride a bike. Real activity, that's real exercise when you get your heart beating up to a certain level. That's strenuous and that I don't do enough of on my own... It should be a priority where it hasn't been in the past but it needs to get back up there on the top again. That's what I'm trying to achieve and not letting the other stuff get in the way. Patricia (moderate impairment, low PA).

The above quote illustrates a modest description of an exercise routine, followed by an assertion that the routine is not 'real exercise.' The participant makes a clear distinction between what she is doing and what she believes she should be doing, stating that real exercise (which she defines as more strenuous than what she is doing), should be a priority. In the context of this quote, the 'other stuff' referred to a family vacation. Patricia later describes the difficulty she experienced getting back into her exercise habit after her relapse:

It's the habit thing [that is keeping me from exercising] because physically I know I can do it. It's like "oh man am I just getting lazy?" It's getting back into the habit and you can't feel sorry for yourself.

Regardless of the difficulty she experienced with her recent relapse, she attributed her inability to return to her previous PA levels as laziness and pointed out that 'feeling sorry for yourself' is an unacceptable reason for not engaging in PA. Against this backdrop of values, it becomes clear that guilt is a logical consequence for not engaging in PA.

Internalized oppression, an important component of psycho-emotional disability, is defined as the 'ways in which disabled people internalize the prejudices and assumptions held by non-disabled people about them' (Reeve 2006, p. 501). The above quotes exemplify internalized oppression; that the individual is berating herself for not adhering to a standard of self-care that

she believes to be appropriate. These beliefs are of course influenced by the broader social world, messages about exercise (ACSM, 2017), neoliberal attitudes emphasizing personal responsibility (Mayes, 2016; Mitchell & Snyder, 2015), and body ideals promoted by her society (Guttman & Salmon, 2004; Heyes, 2006; Markula & Pringle, 2006; Mayes, 2016).

Some described these feelings in direct response to their recent relapse, for example one woman had a strong exercise routine before her relapse and expressed her belief that once she was motivated, she could engage in exercise which would help her return to normalcy. ‘When I was in the hospital, I had physical therapy there... I was very motivated. I was determined. I’m going to get out and be okay.’” She then described what happened after her discharge from the hospital and chastises herself for not putting forth the effort she believed was needed. ‘They gave me some exercises to do at home. I got home. I just collapsed on the couch. I was more worried about starting my new job...[My] priorities were not in the right place.’ This in particular highlights her beliefs that exercise should be important to her and her feelings of guilt over not acting in accordance with that belief in the past. She concluded by expressing her hopes that just coming to participate in the current research study would re-motivate her. ‘I think even coming here today is helpful. That’s why, when you contacted me about the study, I’m like, “Yeah, this will help me get my head in the right place.”’ Leslie (minimal impairment, low PA).

This example illustrates the burden of responsibility to exercise in order to treat MS that many individuals described without directly acknowledging it. The moral imperative to use PA to improve their health (especially as it relates to MS) is accepted (Pond et al., 2010; Wheatley, 2005). This instance also brings up an interesting aspect of the dynamics between researcher and research participant. The participant discusses the role of the current research project in her motivations. Given the power relations and possible presence of social desirability bias, it is

possible certain expressions of guilt were only given because they expected the researchers to believe in certain ideals of exercise behavior (i.e. that the researchers believed that exercise is beneficial for MS and expect individuals with MS to participate in adequate amounts of exercise).

**Empowerment.** When our participants believed that they were doing their best, PA was described as empowering. Statements of pride in self, overcoming obstacles whether due to MS or other barriers, seeing improvement through personal effort, or taking ‘control’ over MS through PA were expressed in relation to a sense of empowerment. The following quote exemplifies feeling empowered from seeing improvement through personal effort and dispelling preconceptions about personal abilities.

Six months ago there was no way I would have been able to go and walk on a treadmill for 20 minutes. No way. I think I accomplished 10 minutes at that time and was exhausted. Now, I’m doing 20 minutes. There’s been a huge difference with it. Carrie (low impairment, moderate PA).

Several participants used specific stories about experiences with exercise or PA that seemed to contribute to their overall beliefs about the role of exercise/PA in their lives.

We can help ourselves through this process. I want to show people that. I went to Colorado and I was climbing these mountains. I didn't think I could climb them. I went up, I don't even know how many miles it was, but I literally killed myself to get to the top of that mountain. I was like this was something you can show people. I have MS and I'm able to walk and I'm able to do these things and be out in the heat. It's not good to be out in the heat, but I was able to do that. Just to show people; just to be a huge, I don't know, role model for people. Natalie (low impairment, moderate PA).

This example also provides an interesting instance of empowerment in the form of defiance of other medical recommendations, namely to avoid overheating. The participant expresses her recognition of the recommendations to avoid exercising in the heat but then her defiance of that recommendation in terms that indicate her ambivalence towards medical

knowledge: 'It's not good to be out in the heat, but I was able to do that.' She presents herself in a way that indicates that exercise helps her to defy certain standard 'MS experiences' and therefore is empowering over MS and also over medical authority related to her experiences.

Strong examples of the direct relationship between exercising for MS symptom improvement and empowerment over MS illustrate the usefulness of exercise for some individuals in being advocates for their lives and their health.

Yeah, the big thing is just going to the gym. That's what I've missed the most. Even before the attack, I would focus a lot of my energy on the gym... I just focus on going to the gym, how much I can get done there, how much I can physically improve myself. That I really miss. Not just that I'm gaining the weight from the 'roids and my muscle tone is getting flabby. That's a constant reminder, but also just going to the gym and exercising, I really feel like I'm accomplishing something. I'm doing something myself to keep the MS at bay. It's my little battle to fight back. Sam (moderate impairment, low PA).

This example is also interesting considering specific words chosen. The relapse is commonly referred to as an 'attack' and in this example, the participant uses the phrase 'my little battle to fight back.' Other health conditions (especially cancer) have discourses laced with war imagery (Penson, Schapira, Daniels, Chabner, & Lynch Jr., 2004). In this case, exercise is the defense against the offence of the MS relapse. Research into the power of metaphoric framing indicates that exposure to metaphors prompts people to apply their knowledge of the metaphoric source used to better understand the situation the metaphor is compared to. In framing a relapse as an attack, it is logical that forms of treatment that address the relapse are considered in related metaphoric terms (battling back). Exercise is taken up in this way (Landau & Keefer, 2014).

Understanding PA/exercise as a source of empowerment is of growing interest in marginalized groups. Previous research suggests that disabled persons use PA/exercise (including sport) as an empowering means to foster a sense of ability, competence, and pride (Pack et al. 2017), facilitate renegotiation of embodiment in an empowering way (Papadimitriou

2008), increase feelings of competence as a social being, foster goal attainment, and social integration (Blinde & Taub 1999), and resist dominant discourse about disability (Huang & Brittain 2006)-the content of our final theme.

Though many described exercise in empowering ways, for some exercise was disempowering especially at the time of the MS relapse, for example: 'I didn't really want to try to do anything. I guess it diminished my interest in doing things.' Elizabeth (moderate impairment, low PA). Also, a few participants seemed to be very aware of a tension between guilt and empowerment. One participant described her mindset in relation to reaching exercise goals:

Sometimes I feel like if I don't get there (do enough exercise), then I disappoint myself, and I don't want to be disappointed. I'd rather just do what I can do and then say, 'Oh, isn't that good? Look what I did.' I'd rather do that than say, 'Oh, I didn't do what I said I was going to do.' I could say, 'Oh, I did more than what I thought I could do.' That's me. Rebecca (moderate impairment, high PA).

The context of this quote provides evidence that this conception is one that has come with time and conscious effort.

### **Theme 3: Defiance of disability (disability preventer, disability eraser)**

The final theme concerns itself with the perceptions of the role of PA as a means to negotiate disability. This theme is related to the discussion of treatment for MS but is distinguished by the emphasis on removing or preventing a conception of disability specifically and not just symptoms of MS. Importantly, all of our participants discussed disability and impairment from the perspective of a medical model of disability. Therefore, although we discuss impairment or disability separately, our participants did not make that distinction. We will use

‘impairment/disability’ when we are discussing their views, but use impairment and disability separately to provide our interpretation and discussion when appropriate.

The connections between an MS relapse and future disability was not always clear or explicitly discussed, however some did express that the motivation behind improving fitness to better handle future (inevitable) relapses was to lower the chance of residual impairment. By using hand gestures to show higher or lower levels of impairment (‘here’, ‘this point’), the participant (Rebecca) explains that she hopes her fitness will keep her from having a higher residual impairment following relapses.

If it comes along, at least if I work on it and I'm better, and a relapse comes along, then I'm at least at this point instead of at this point. When I relapse, if I relapse from this point, maybe I'll only go to this point... Instead of going from here to here, maybe I'll just go here to here. (moderate impairment, high PA)

Furthermore, some participants discussed the direct and negative impact of acute impairment during relapses on body image and identity:

Oh my gosh, it affected my body image. I didn't want to go and be around people. I just didn't feel good about myself. I felt kind of like you lost part of yourself; like your identity was just taken away from you. Natalie (low impairment, moderate PA)

In research conducted among women with MS related to having an episodic disability, the theme of ‘not looking disabled’ was explored. Vick describes the challenges of those with episodic disabilities that fall outside of the classic, visible disabilities others can accept as disabilities (Vick, 2013). While there is a desire to have MS-related impairments be accepted (and legitimized) by others, many of those we interviewed clearly expressed the desire to prevent future visible disability (especially related to mobility). In some ways, exercise then becomes a way to pass as non-disabled, while concurrently being interpreted as something that can bring on increased impairment (see theme 1).

Many individuals specifically described fear of future impairment/disability as motivation for engaging in exercise with the negative impact on body image during the acute relapse feeding that fear. ‘Move it or lose it’ was a commonly used expression to describe motivations for exercising in the context of disability. ‘I am convinced absolutely that if I don’t engage in physical activity or whatever you want to call it, if I don’t get up and move, I’m not going to be able to.’ Maria (moderate impairment, moderate PA).

I want to ride a bicycle again. I miss riding, and I miss jogging. I miss all the stuff that I used to do. So that's the motivation... Because stuff I've read, that eventually people can change into progressive\*. And I don't want that, I don't want to ... I don't want that. So I know that I got to keep doing stuff. So that's the kind of motivation. Tammy (moderate impairment, low PA).

\*(Progressive MS is another form of MS that is characterized by progressive deterioration of the CNS and ever-increasing symptoms.)

The wheelchair was often used as a representation of impairment/disability throughout the interviews. Relapses then are periods of time when a wheelchair becomes more of a possibility or sometimes a reality.

Like I said, I don't want to end up in a wheelchair. I don't want to be dependent upon a wheelchair. I don't want to be dependent upon the walker. I know I can't move around because I used to be able to walk wherever. Bonnie (moderate impairment, moderate PA).

The individual’s identity is called into question anew because of the current lack of mobility or ability. Exercise and PA then become a way to avoid impairment/disability even as inability to engage in exercise because of the current relapse is an indication of exercise’s inability to prevent impairment/disability. Bonnie’s repeated use of the word ‘dependent’ hints at fears related to disability, i.e. that disability is a loss of independence that comes with loss of mobility.

Exercise serves as a way to address the uncertain ‘threat’ of impairment/disability caused by having MS. The embodied experiences of lost mobility, diminished strength, or increasing

difficulty in performing daily tasks prompted action in the form of exercise in order to reverse the progression towards impairment/disability.

March, I was just slowly, slowly getting weaker and weaker and weaker and weaker and weaker. I had to do something absolutely. One of the doctors had mentioned [exercise]. I said I've got to try. I've got to do something. When I slowly started seeing my strength build, that was why I absolutely can't stop that. I can't afford to go back to the way I was because if I had not started the exercise, I have no idea where I'd be right now as far as the strength of my legs, my ability. Nope, no idea. Carrie (low impairment, moderate PA).

Some reflected on the ways their healthcare providers encouraged them to exercise as a way to avoid further impairment/disability. These included neurologists and physical therapists. Many seemed very comfortable expressing their concerns to their healthcare providers in hopes of being given solutions and treatments to avoid disability.

He wants me to be up and constantly moving. He knows that I have no plans on being in the wheelchair at all, period. Not something that I'm willing to take. His thing is always, get up, keep moving, keep moving, get up. Kayla (moderate impairment, high PA).

Exercise is used as a way of transforming (or maintaining) a desired identity as non-disabled or reinterpreting what disability means. The person with MS who decides that having an MS identity does not have to mean being disabled, or even that being disabled does not have to mean being inactive can use exercise as a means to reimagine an MS/disabled identity and push back against negative stigmas. This also became somewhat apparent in relation to sports activities for individuals with MS; Tammy stated the following:

Yeah, it'd be fun. Why not? You see all the time... the commercial they have where kids weren't able to do stuff but this hospital was helping these kids and they're like, I can bowl now or I can dress myself or I can do whatever it is. They were saying they can do that now, where they couldn't do that before. They can walk. They got crutches or something. Why not, you know? Just because our bodies aren't right and are broken, doesn't mean our spirits have to be broken. It really doesn't and I hope that like in general with me, having hopes and I think that's good... But with the exercising ... I think making a team would be awesome. Just have fun. Why not? (moderate impairment, low PA).



Here, the identities related to having a chronic disease or a disability fall into established (medical) categories in terms of their definition (i.e. bodies aren't right and are broken) but she uses sports and exercise as a way to renegotiate parts of these identities for herself in positive ways. Research into the impact of sports on identity among disabled populations underscores the positive role of PA participation (in elite and recreational groups) on combating medical model views of disability and enhancing self-concept (Huang & Brittain, 2006; Kissow, 2015; Pack, Kelly, & Arvinen-Barrow, 2017). Sports and exercise become empowering ways to transform perceptions of the impact of having MS or being disabled (Lundberg, Taniguchi, McCormick, & Tibbs, 2011). Exercising individuals with MS problematize current cultural assumptions that individuals with chronic diseases are sick, or weak. However, in emphasizing the prevention of disability through exercise, medical or individual model of disability assumptions about disability can be reified (i.e. that disability is weakness, and undesired).

I had to keep going. I had to be able to walk. I had to be able to function. Exercise built that up to me and showed me, 'Hey, you can do this.' I absolutely have to keep with it. Carrie (low impairment, moderate PA).

This example illustrates the utility of exercise to prove that the MS body is strong and capable (challenging assumptions about MS) but places disability (in the form of immobility or dysfunction) in the place of the abject (Wendell, 1996), the thing to be avoided and exercise is the empowering agent to do so. Exercise is empowering within the broader social and cultural world which devalues disability, and values health, vitality and fitness (Pond et al., 2010).

Research among women with varied chronic illnesses confirms a tendency towards rejecting a 'disabled' identity and associating disability with stereotypical and permanent situations rather than their fluctuating and incomplete physical realities (Crooks et al., 2008), although those with chronic illness are not the only ones to reject a 'disabled' identity (Watson,

2002). Sense of identity in general (not necessarily associated with disability) has been explored among adults with MS (Grytten & Måseide, 2005; Strickland et al., 2017). Using an IPA approach, Mozo-Dutton et al discussed the ways that individuals with MS felt their bodies no longer belonged to them, missed their previous self-concept, and incorporated MS into a sense of self, although often begrudgingly (Mozo Dutton et al., 2012). Our analysis confirms these themes however our emphasis on disability identity rather than sense of self allows these findings to be contextualized within the broader literature on chronic disease in disability studies (Driedger & Owen, 2008; Ferrie & Watson, 2015; Hughes, 2014a) and medical sociology (Thomas, 2012).

### **Limitations**

Though the researchers made efforts to reduce bias within the interviews, one limitation of the current study is the impact that the researchers and research location may have had on the participants' responses. Half of the participants were interviewed in a room within the exercise lab of the research group, a space that is filled with exercise equipment, and denotes a scientific feeling to exercise. Participants interviewed here may have felt more pressure to explain their feelings about exercise in medical and positive terms and may have been more likely to admit to 'insufficient' exercise behaviors given beliefs about the research team (i.e. that they value exercise). It is possible that the discussion of guilt was influenced by these factors. The other participants were interviewed off-site. Due to the size of the groups and the other differences present, it is not clear whether these participants discussed guilt and shame differently than the other participants who were interviewed in the exercise lab. Bias is a highly debated topic in qualitative research (Roulston & Shelton, 2015). We do not claim that our participants' responses

were ‘untrue’ only that we may have had a greater influence in the discussions related to guilt. Furthermore, we acknowledge that we provided no commentary on the impact of gender, race, or socioeconomic status on the relationships between PA, impairment and disability identity. We recognize the complexity of the impact of these factors on the experience of a disabled person, but as this was a preliminary, exploratory study, we were unable to explore these factors.

Lastly, our sample included mostly those with mild-moderate impairment. Their relationships with disability identity are likely most ambiguous due to lower levels of impairment (Taleporos & McCabe, 2005). Indeed, severity of impairment is associated with disability identification (Bogart, Rottenstein, Lund, & Bouchard, 2017). Further examination into the experiences of those with severe MS impairment is needed.

### **Conclusions**

In this paper, we have provided examples of the ways that individuals with MS perceive the role of PA and exercise in their lives, as part of their management of MS, as it relates to MS relapses, and as part of their negotiations of a relationship with an identity as disabled. The interviews provide descriptions of both guilt and empowerment related to PA, as well as examples of the motivations behind PA and exercise participation in this population (namely for managing MS symptoms and avoiding impairment/disability). The interviews further illustrate what is at stake with an increasingly medicalized form of exercise and this is a complicated process of embracing an identity as disabled.

Because impairments typically associated with MS come and go for some individuals, they may not necessarily embrace an identity as disabled, though it may be beneficial. By emphasizing ‘fixing the body’ with exercise, individuals with MS may be impeded from

cultivating a positive sense of disability identity (Wendell, 1996). Embracing and cultivating a positive identity as disabled is associated with lower rates of anxiety and depression among adults with MS (Bogart, 2015). Rates of depression among the MS population are quite high, estimated at approximately 50% over the lifetime (Feinstein, 2011), therefore the ramifications of this relationship are relevant to this population. Interestingly, there is also evidence that exercise participation can reduce symptoms of depression in the MS population (Ensari et al., 2014). The relationship between exercise, depression and disability identity among those with MS is complex and merits further examination and consideration when using exercise as part of comprehensive MS care.

With increasing efforts to promote PA in comprehensive MS healthcare, there must be equal recognition of its perceived dynamic and contradictory roles. The emphasis on using exercise as a form of individual responsibility over MS can be at once empowering and uncertain. Some of these interviews provided instantiations of feeling empowered by taking control over MS and preventing the increased impairment that accompanies MS relapses, other interviews revealed contradictory statements about exercise and exercise promotion. On one hand, the interviews reveal the ways in which exercise has failed to prevent relapses; on the other hand, they illustrate the ways that being unengaged with exercise can lead to feelings of guilt. Both of these participant discourses should inform the revision of active exercise promotion efforts. We cannot deny that engagement in exercise is empowering and meaningful for these individuals. It is even helpful at times and does lead to positive outcomes related to MS, but we cannot hoist upon individuals with MS the burden and responsibility for an unpredictable and uncertain condition. We urge providers to carefully consider the ways that exercise promotion could potentially be conflated with prevention of disability as this can lead to a potentially problematic process of embracing a positive

sense of disability identity. Likewise, exercise promotion efforts which can empower individuals to challenge problematic notions of MS and disability identities can and should be explored and employed.

## CHAPTER 4: METHODOLOGY AND METHODS

### Research Paradigm

This research is underpinned by a subjectivist epistemology, where knowledge is the product of the interaction between researcher and participant, understanding that participants make multiple meanings of reality and the researcher is not an objective third party observer. It is important to note the motivations behind the production of this particular knowledge (the current dissertation project) are first to critique current practices of exercise promotion (that emphasize medical benefits and reduction of disability) on the basis of the potentially negative impact this has on an individual's embodied experiences with exercise and disability, and second to inform the alteration of future exercise promotion practices as well as exercise discourse in general. Therefore, the primary axiological assumption for my research project is social justice; the alteration of discourses and practices related to exercise promotion that are victim-blaming, are laden with guilt or shame, disrupt the ability of individuals to identify positively with disability, and strip exercise of other potential meanings and values.

Central to the social-relational model of disability is a non-reductionist, materialist ontology of the body that is constructivistic but not culturally deterministic. Thomas underscores the importance of the qualifier "non-reductionist" by arguing that even impairment is bio-social, stating the need for a "theoretical framework that recognizes the social dimensions of the biological and the irreducibly biological dimensions of the social" (Thomas, 2014) p.14. Some would argue that this precludes the inclusion of poststructural constructs within my research paradigm, however Hughes describes poststructural conceptions of the meaning of the disabled body by describing the *non*-disabled body in a way that does not necessarily discount the basis of

a biological difference between bodies, rather they give primacy to the cultural representation instead:

The non-disabled body is usually described as ‘normal’. But what do we mean by ‘normal’? Clearly, it is not a precise term, more of a statistical average. In other words, in reality, the normal or non-disabled body does not exist. What does exist is the linguistic convention or discourse of normality that conveys something to us about bodies and helps us to make some sense of them. If the non-disabled body does not exist in any essential sense, then the same applies to impairment. It is a metaphor, a cultural representation that, in modern times, has become located in a negative language of defect and deficit. (Hughes, 2014b) p. 58

Beyond the scope of my project, yet relevant to my conception of embodiment, disability and impairment is a need to understand the discursive practices that yielded some bodies as defective and others as normal (ongoing work in disability studies). Regardless of the understanding of impairment as a denotation of suffering or as a linguistic term, currently, many people perceive certain embodiments in terms of suffering, pain, discomfort. Therefore, I have adopted the useful concepts of discourse and power relations from poststructuralist paradigms to contextualize major influences on the uptake and meaning making of exercise-related information and messages, and impact on disability identity negotiation while also considering a material and complex embodiment.

Given my subjectivist epistemology and non-reductionist, materialist ontology that is constructivistic but not culturally deterministic, an interpretive phenomenology is best suited for my research questions and goals. Specifically, Interpretative Phenomenological Analysis (IPA) has been a useful method for “exploring in detail how participants are making sense of their personal and social world...” (JA Smith & Osborn, 2003) p. 53. Therefore, this approach coupled informed by poststructural constructs of discourse, subjectivities, and power-relations is suited to explore experiences and interpret the meanings of those experiences against models of

disability, discourses around exercise and power-relations present in both the “disabled-abled” dichotomy and “exercise promoter-exerciser” relationship. IPA’s use in health-related studies (Brocki & Wearden, 2006), exercise studies (Borkoles et al., 2008; Richardson, Smith, & Papathomas, 2016) and among adults with MS is well-documented (Borkoles et al., 2008; Mozo Dutton et al., 2012).

The social-relational model of disability provides a framework for understanding that the experience of the individual is a function of his or her embodiment (including impairment), the social and political landscape of his or her world (that society oppresses, has certain ideals and expectations surrounding illness, and this includes history, language and power dynamics), and the psychological impact of oppression, stigma, prejudice and discrimination (Reeve, 2002; Thomas, 2007). An interpretive phenomenological paradigm allows for the exploration of the meanings that persons with MS ascribe to their embodied experiences with exercise in the context of each of these factors and how this has impacted the constructions of their self-concept in relation to disability. By using the above-mentioned poststructural constructs, the relevance of this research to the discursive practices surrounding exercise promotion in this population can be more clearly visible.

Major critiques of interpretive phenomenological paradigms (from poststructuralists) are that interpretive projects are too individualistic in nature and lack emphasis on cultural context and power relations. However, the use of both interpretative phenomenological methodology and a poststructural paradigm has precedent. Ashworth has argued that discourse analysis can be conceptualized as an extension of hermeneutic phenomenology. Accounts given by research participants about their lifeworld are interpreted “as expressing one or more culturally available discourses.” (Ashworth, 1997) p. 223. Using this framework, Johnson et. al. sought to



understand the ways that first-time mothers felt about body changes during pregnancy. They first conducted an interpretative phenomenological analysis to understand the meanings ascribed to weight gain by the participants themselves. They then conducted a Foucauldian discourse analysis in order to examine the ways participants' account reflected the "discursive resources of their culture and give insights into the ways these set up subject positions." (Johnson, Burrows, Williamson, & Ly, 2004) p. 394.

Among research in disability studies, there is increased recognition for the need of a sociology of impairment (the extension of Thomas' bio-social understanding of impairment effects) to underpin phenomenological accounts of impairment and disability. "Phenomenology is much more convincing when it starts from the principle that embodiment is always, simultaneously, a personal and social dynamic. Couched in these terms, phenomenological accounts can offer important insights into the corporeal, social, subjective, and affective experiences of embodiment." (Sherry, 2016) p. 731. Revisiting Siebers' disability identity politics, phenomenological explorations of disability are inherently tied up with exposing the dominant ideologies of society because of the sociocultural "baggage" always already tied up with this category: "... [disability is] a social location complexly embodied. Identities, narratives, and experiences based on disability have the status of theory because they represent locations and forms of embodiment from which the dominant ideologies of society become visible and open to criticism..." (Siebers, 2008) p. 14. This not only justifies the use of both an interpretive phenomenological paradigm and constructs of poststructuralism but illustrates that this approach may be an effective means of social change, illustrating problematic discourses of exercise and disability and providing insight into ways that these discourses may be altered or that individuals are resisting them.

## **Data**

The data I used in this research project come from 2 previously completed qualitative interview studies (heretofore referred to as interview subsets), both of which I was heavily involved in conducting. Though the specific aims varied, both had at their core a discussion of exercise and its value and meaning. The first, “RELAPSE” was an exploration of the ways that individuals described exercise in relation to MS relapse, specifically, we asked about the impact of MS relapse on the participants’ exercise behavior and their understandings of the role of exercise in their MS care. The second was a photoelicitation project (PEMS) where 23 individuals were given cameras and asked to take pictures of things/places/people that made it difficult to engage in exercise or that made it easier to participate in exercise. This was followed by an interview where individuals were asked to describe the pictures taken and to discuss the role of exercise in their lives as well as what barriers and facilitators existed in relation to physical activity. All interviews were audio-recorded and transcribed verbatim previously. Interview guides are found in Appendix A Both interview project protocols received approval for the Institutional Review Board when originally conducted. Study data were de-identified prior to this secondary analysis and therefore the active IRB status for the two subsets was not renewed.

In order to select a sample of interviews for re-analysis, I read through transcripts of all interviews comprising the interview subset. I looked for interviews that were rich in content, that had signs of quality interviewing skills (good probing, following the direction of the participant, minimal or no leading questions, detailed follow-up questions), and that had sufficient discussion related to my topic.

## Analysis

I analyzed the interviews utilizing an interpretative phenomenological analysis (IPA) approach. I will describe several key tenets of IPA (some of which are tenets of phenomenology generally) that guided my analysis. First, the centrality of the body in experience:

Your body unfolds for you a world which is particular to you and different from the world which is disclosed through your friend's body. IPA, with its starting point in the unique intersubjective experiences of the individuals inevitably attends to the body as it is lived and experienced.

The second is the lens of sociocultural and historical meaning: "All of this is not to neglect the fact that the lifeworld of the individual is socially and historically contingent and contextually bounded" (Eatough & Smith, 2014). How individuals make meaning of the embodied experience within the context of the lifeworld is the first level of interpretation (Heidegger's "hermeneutics of factual life") (Moran, 2000, p. 233). Therefore, seeing the ways that participants interpret their embodied experience is the first lens I will use in my analysis. A third key tenet of IPA is its idiographic nature. Each interview is treated as a case study, with a focus on the specific rather than the generalizable. Furthermore, with a more intense reading of each individual interview, there comes the increased possibility of making connections between multiple aspects of one participant's interview. This is especially important given my research questions of understanding the contradictory roles that exercise may have. The researcher performs the second level of interpretation, which, in the case of the current study comes through making connections between the participants' perceived meanings of the exercise and to concepts and constructs of the Social Relational Model of Disability, the medicalization of exercise and poststructural understandings of exercise and disability.

For each interview, I began with a printed copy of the transcript with space for notations. I listened to the interview as I read through the transcript. I made notes about tone, fixed errors in

the transcription, and added notes about the audio recording that were unable to be captured from the transcript (e.g. laughter, loud language, prolonged silence, stuttering etc). I then re-read the transcript making notes along the left-hand margin and highlighted passages that stood out. These notes were specific, and longer (e.g. *activity in her front yard allows her to have a sense of pride*). I then wrote a summary of my impressions from the interview as a whole (e.g. *Former athlete, dreads exercise, empowered within value system where exercise=good, inactivity=bad/gross/lazy. Enjoys exercise that is freeing. Constant vigilance over self and others to exercise, to prevent loss. Source of stress, tension, anxiety.*) I then reread the interview with the goal of transforming my notes into more precisely descriptive terms (Polkinghorne, 1989) making new notes (themes) on the right-hand margin that were more succinct (e.g. *I am my own worst enemy* on the left becomes *schism in self* on the right) and began a list of these themes on a separate piece of paper. After this third reading I looked over the list of themes and compared it to my summary to ensure that all of my initial notes were represented in the list of themes I created. I then completed a fourth reading, this time fitting together themes into larger groupings (superordinate themes) and including brief quotes and line numbers from the transcript as examples of the different subthemes (e.g. Superordinate theme: Dread, Subthemes: Reluctance (“Fine, I’ll get off the couch” line X); Source of stress (“It’s a constant, I’m constantly thinking about it and it stinks” line Y). I summarized their meanings of exercise and disability and began to make notes about the sociocultural factors influencing these meanings (for example, *conflicted about exercise because family sees her exercising and discounts her MS. Connects to disbelief about invisible symptoms and disability*).

At this point, I set the transcript, notes and list of themes and quotes aside and began the same process again with another interview, thereby treating each interview as a case study and

creating a list of themes for each individual interview. After completing analysis for several interviews in one interview subset (5-7 interviews), I compared lists of themes to find similarities and divergences. I began a master list of themes, subthemes, and quotes. This included divergences as a subtheme of each superordinate theme.

Once I had completed analysis for several interviews in both interview subsets, I compared my 2 master lists of themes. I read quotes from potentially related themes to understand the similarities and differences between the themes and consolidated where appropriate and redefined where necessary. At this stage, I began looking at the themes and quotes as descriptions of constructions and discourses surrounding exercise, health and disability. Specifically, I began looking critically at the master list of themes to understand what social ideals participants were appealing to in their descriptions of the roles of exercise in their lives, e.g. a social imperative to be thin, strong, non-disabled; or the need to avoid inactivity at all costs and at all times as a form of constant vigilance (docile bodies). I also looked at the ways the themes demonstrated certain subjectivities (e.g. participant's deference to medical authority over MS vs. questioning medical authority in personal situations). Keeping with IPA's idiographic approach, I returned to the transcripts of several interviews as I sought to contextualize the themes in terms of discourse, power relations and subjectivities.

At this stage, I conducted a new literature search of the superordinate theme categories as well as the poststructural themes in the context of exercise and disability. The results of the IPA analysis are presented first, then the results will be contextualized within the discussion according to the poststructural themes discussed and within the framework of the Social Relational Model of Disability.

## Quality

Two important criteria for determining quality within IPA studies are internal consistency and sufficient excerpts. Therefore, in writing the results, I have included quotations for each subtheme presented, as well as divergent quotes for the superordinate themes. Furthermore, I have sought to demonstrate that the description of these results are not only internally consistent, but consistent within the broader literature with the discussion section.

An important portion of this analysis is the interpretation. Peer debriefing is one method for improving the quality of the interpretation that is commonly used with IPA. I therefore engaged in peer-debriefing at several stages throughout the analysis with two separate peers. These peers are knowledgeable on the methodology and the general research topic and while each was involved in the original research study (one for PEMS and one for RELAPSE), neither were directly involved in the subsequent analysis I performed. Therefore, they were familiar with the interview and the participants but not in the context of my new research questions. I discussed connections, themes and implications (content for discussion of results). These peers were able to point out holes in the logic of my interpretation, and discussed how different conclusions might be drawn from the same data. (Markula & Silk, 2011).

Furthermore, throughout the entire process, I have been mindful of Kvale and Brinkmann's seven stages of validation of qualitative research (Kvale & Brinkmann, 2009). They start with the assumption that *validity* is a social construction and from there emphasize the importance of *quality* at each of 7 stages. They are *thematizing* which includes the soundness of the theoretical suppositions of my proposed study. *Designing* is the stage that emphasizes the use of appropriate methods to answer the research questions *and* that are beneficial to the human condition. The *Interviewing* stage had already been completed as previously mentioned,

however, I evaluated the quality of the interviews I used as part of my subsamples and will only include those which involved “careful questioning as to the meaning of what is said, and a continual checking of the information obtained” (p. 249)). The stage of *transcription*, though previously completed, was improved by re-listening to interviews and including notes with the transcriptions). The *analysis* stage is the most extensive stage and involved continual questioning of the logic of my interpretations and revisiting the interview transcripts for confirmation or alteration of those interpretations.

The stage of *validating* was addressed by including peer-debriefing as part of my analysis. The quality of the final stage of *reporting* is strengthened by including a wide range of quotes for each theme, showing the relationship between participants’ experiences as well as the nuance of individual meaning.

## **CHAPTER 5: RESULTS**

### **Participants**

I selected 12 interviews from the PEMS interview subset and 12 interviews from the RELAPSE interview subset. Two participants completed both interviews, Maria and Mitch, and therefore this analysis represents interviews from 22 distinct participants. In cases where a theme is more prominent in one subset over another, the discussion makes this clear. Participant demographic information can be found in Table 2.

Our final sample of participants ranges greatly in terms of demographic information and history with MS. This is important to note given that my chosen methodology generally emphasizes a small homogeneous sample. However, I compared themes across groupings of age, sex, impairment group, years with MS and GLTEQ score and found some differences between groups but generally the themes were consistent across all groups. In the themes where there were group differences, I include discussion of the differences and for which groups those differences were apparent. One final note, as the RELAPSE interview was previously analyzed for the purposes of understanding the role of exercise in disability identity (see chapter 3), I used more quotes from the PEMS subset in the description of the results though both subsets are represented.

### **Organization**

The results will be organized as follows. There will be three main sections, exercise, identity and disability. These sections reflect my original research questions, i.e. what are the roles ascribed to exercise by people with MS, and how does this impact the negotiation of an identity as disabled? Each section will include 3 main parts, the themes and subthemes related to the section



from the IPA analysis, and major instances of divergence from the themes. See Table 3 for a table organizing sections, themes, subthemes, and exemplary quotes.

**Table 2. Participant Demographic Information**

Participant Pseudonym	Gender	Age	Employed (Y/N)	Race/Ethnicity	Impairment Group*	Years with MS	GLTEQ score**
Maria (P,R) <sup>§</sup>	F	61	N	Latina	Severe	25,26	30,26
Amanda (R)	F	36	Y	White	Mild	9	18
Natalie (R)	F	30	Y	White	Mild	1	36
Shawna (R)	F	70	Y	American Indian	Mild	35	8
Leslie (R)	F	42	Y	White	Mild	12	3
Tammy (R)	F	41	Y	White	Moderate	18	0
Patricia (R)	F	64	N	White	Moderate	20	11
Carrie (R)	F	48	Y	White	Mild	3	21
Kayla (R)	F	33	Y	Black	Moderate	11	64
Bonnie (R)	F	63	N	American Indian	Moderate	--	21
Sam (P,R)	M	44	N	White	Severe	13,14	22,25
Larisa (R)	F	27	Y	Latina	Mild	2	21
Joyce (P)	F	57	N	Black	Mild	8	--
Dana (P)	F	28	N	White	Mild	1	31
Elaine (P)	F	49	N	White	Mild	9	41
Justin (P)	M	38	Y	White	Mild	9	54
Leah (P)	F	32	N	White	Severe	4	0
Angela (P)	F	63	Y	Black	Severe	23	9
Amelia (P)	F	65	N	White	Severe	41	9
Michael (P)	M	67	N	White	Severe	14	20
Ellen (P)	F	57	N	White	Severe	13	30
Jessie (P)	F	55	N	White	Severe	22	21

\*Determined through self-reported EDSS=Expanded Disability Status Scale. Mild level of impairment=0-3.5, moderate level of impairment=4.0-6.0, severe level of impairment= 6.5+. (Kurtzke, 1983)

\*\*GLTEQ=Godin Leisure Time Exercise Questionnaire. Low level of exercise participation=0-13, moderate level of exercise participation= 14-23, high level of exercise participation=24+. (Godin, 2011)

<sup>§</sup>Indicates the interview subset: P=PEMS, R=RELAPSE, Maria and Sam completed both interviews.

## Section 1: Exercise

The primary aim of this study is to understand the many and often contradictory roles that individuals with MS ascribe to exercise. In this section, the phenomenon of exercise or physical activity engagement is described as well as interpretations given by participants as to the

meanings and roles of those experiences. Three main themes carried throughout the two interview subsets: Constant Vigilance: I *should* Exercise; Exercise as Productivity and Social Engagement; and Exercise as Medicine and/or Self-Care.

**Theme 1: Constant Vigilance, I *Should* Exercise.** Participants described the need to exercise often as an imperative. They felt that they *should* exercise but the source of the feeling of “*should*” was often unidentifiable even if asked directly. “I should exercise” was an unquestioned universal. Some referenced knowing how they felt after exercise or knowing the benefits of exercise as reasons for this imperative. Reasons why participants felt they should exercise were most often related to staying healthy and preventing future impairment/disability from MS. For several participants, they felt they should exercise in order for weight control purposes as well. Because of this imperative, many felt a sense of guilt, shame or described themselves as lazy when not engaging in exercise and this was a particularly troubling cycle for some. Importantly, this is likely common to many individuals, not just those with MS however, for these participants, the general health imperative was compounded by the imperative to prevent, or reduce MS-impairment. The nagging at the back of the mind to exercise was described as constant. This presented a source of stress and exercise was therefore something to dread and to feel guilty about not engaging in. This is reflected by Dana’s discussion:

I mean exercise plays a big role [in my life]. I think about it every day, think about it every couple hours actually. I'm like "Oh what am I gonna do, should I go do this? Is today really good? Well I could take today off, like today is not a big deal. Oh no you really need to go today." Like it's a constant struggle and I think a lot of people have that, am I feeling up to working out after work today? It's a constant, I'm constantly thinking about it and it stinks, but if I don't think about it, then it's-- yes I'm less stressed but then later on I'll be more stressed because I wasn't thinking about it.

Her internal dialogue reflects her evaluation of how she feels physically (this includes her level of fatigue from MS, as well as any other symptoms that might be bothering her), how her day has gone otherwise, and her comparison of this evaluation with her feeling that she really should ‘work out.’ This is described in mainly negative terms, but she notes that the stress keeps her from feeling something worse; for her, that would be guilt.

...once you get to that point and you're like Yes! I got out. I did this today. I feel much better about myself and I don't feel as like depressed that day... You know by like the end of the day, it's like 5'oclock and I still have to make dinner and I haven't done anything and I'm like "God, I feel lazy and gross and like why didn't I get out and do that this morning" you know? And then I feel bad about myself and then next day comes around and I'm just as tired and you know it's a cycle.

For Dana, the ‘need’ to exercise is a source of stress and a source of guilt. Constant vigilance is described as nagging, demotivating or motivating in negative ways. However, for others, constant vigilance played out in more positive and motivating ways. Consider the experience of using two activity monitors in Elaine’s case:

Well, it's because [the watch] is easier to check because it's on my wrist and [the information] is on my phone. If the one that's on my wrist goes dead, I can put the other one back on, I still have the other one and it synchs back up with what this one was saying, which is amazing. I have a goal and I'll push myself harder because I know where I sit during the day and this one, every day every hour, this gives me a 250-step goal every hour and so I made my 250 steps for this hour. At 1 o'clock it's going to come up that I haven't walked 250 steps so it's going to come up and say I walked zero steps at 1 o'clock so I get up and I jog in place for 250 steps.

Elaine enjoys being able to constantly check her progress towards her goals and knowing when she ‘should’ do more. She discusses getting a new activity monitor for her waist but keeping the one for her wrist because she recognized that each monitor would be tracking slightly different activities and wanted to be able to track as much as possible. This reflects her perspective that opportunities for physical activity are everywhere. She discusses dancing while

doing household chores, walking every aisle at the grocery store, walking up and down the stairs, and parking far away from buildings for extra physical activity.

Larisa did not have the same orientation to physical activity monitoring, it was not necessarily empowering such as in the case of Elaine though was motivating at some times.

Consider Larisa's two different perspectives related to constant monitoring before and after her recent relapse:

Right before [my relapse, my physical activity level] was zero because we were on vacation. I mean like some days we walked... I didn't take my Fitbit. That was my theory of non-commitment. It's not coming with me because I didn't want it telling me you walked 2,000 steps the whole day today. I don't need that.

We started going to a gym at the end of January again and since I had a relapse I am not going to start running. I felt still like not completely balanced when we started going back to the gym. So, I was like walking at 3.5 mph but I am doing it now for 45 minutes so that is a decent amount of time. We were going for like 3 weeks, we were doing so great and then I got sick and so we stopped going. Then he got sick last week. We really need to start, I'm like today we are going. I am currently on a Fitbit challenge and I am in fourth place. I need steps.

Her declarations at the end of these two passages, "I don't need that" and "I need steps" seem contradictory but reflect her ability to choose when and how the activity monitor works for her. She does not want to feel guilty at times about her level of physical activity, but at other times, she wants that level of motivation to help her engage in the amount of physical activity that she thinks she 'should.'

Another manifestation of constant vigilance is more related to performance. Justin is an avid participant in Tae Kwon Do and discusses why he feels he 'should' always be doing something instead of watching TV.

We're talking about TV, entertainment system-type stuff. So sedentary stuff. You're sitting there and you're watching and you're probably not doing anything. You probably should be doing stretches or push-ups or something while you watch that, but let's face it, that doesn't happen very often. The idea is I should be stretching or doing something else because I'm trying to do better on a kick in taekwondo, of which, I

know my lack of flexibility in an area is preventing me from actually doing that better from what I currently do. That's one example.

His goals are slightly different than Dana's or Elaine's, and he feels he should be in a constant state of activity in order to reach his goals for Tae Kwon Do. However, elsewhere he discusses that he is constantly thinking about opportunities to be active in order to feel better generally:

Today's a good example, I did something a little different, but I got myself cycling in the morning for at least a thirty-minute timeframe, whatever, and then getting to work, energy level is so much different. It really amps me up and provides some level of focus through the day. It's just something I've been kind of playing with. And there's really something there... Where that should comes from is knowing that state of feeling of feeling better, not tired, downtrodden or what have you. Just the feeling of feeling better, and I guess you could say, "Is it a positive or a negative thing?" Is that positive influence versus I don't wanna do that I want to stay here.

There was a general undercurrent of urgency in the need to engage in physical activity which was amplified by an awareness of bodily changes and a need to manage MS. One participant, Amelia, described that she believed her body was in a constant state of 'stiffening up' and if she sat too long without engaging in an activity of some kind, she would stiffen up too much.

I feel way better when I do it [exercise]. Yeah, it is easier to move around. I'm less likely to be hesitant with things like climbing stairs... My motivation is just so that I can move because otherwise I will stiffen up. If I get stiff, it will just most likely be the old domino effect. It's just going to get worse.

A few other participants also discussed stiffness and the urgency to keep moving to avoid it.

Michael used an even stronger word, atrophy. He believed that as soon he got out of the habit of exercise, his muscles would start to atrophy.

We got new equipment, and three days a week I go down there to exercise, and I'm not sure if it's related to the MS or not, but for me, atrophy sets in just incredibly fast. If we go on vacation, we go usually three times in a year, and for 13 days, and when I come home, it takes a while to get back into the routine. It seems like when I hit a good level,

next month or so, it's vacation time again, and it's like, "Oh my God, now I got to start all over again." ... If you want to maintain, you have to have physical activity. Like I said, if you lay around, atrophy sets in, and then you might want to, but your legs just aren't going to do it.

For Michael, the main reason for his constant vigilance was to avoid this negative outcome of 'atrophy' and the accompanying loss of fitness that he would then need to work extra hard to rebuild. This ultimately became linked to his feeling of responsibility for his family.

And sometimes you can exercise and sometimes you can't, and I'm not going to ... Like if I've got an appointment on Wednesday, I can switch my exercise from Wednesday to Thursday, and I'm not going to go into some withdrawal. It's not going to throw my week off or something like that, but at the end of the week if I don't have two exercise days, that will bother me because I feel like that's something that I have to do... I don't want to be a burden on [my family], this is my responsibility, and this is what I have to do to make sure that I'm mentally and physically able to carry on. I've got a fiduciary responsibility to provide, for lack of a better word, because if I die, obviously my pension dies, and I want to be sure that they stay as comfortable as we have it now. I don't want them to have to change their style of living, and so I've got to be alert, and I've got to be physically capable so that they don't have to watch over me constantly.

Managing MS symptoms and impairments was the biggest reason for the sense of urgency. Patricia discusses the need to prioritize exercise because of the uncertainty of MS. She does not believe that she can control MS with exercise but that she can prepare her body for relapses so that they will not affect her as much.

I think that the main thing with exercise is like if [a relapse] is going to happen that's out of your control. You can't determine that, but you can control how physically fit. Otherwise, you could be ... so I think it's the best thing is to be as physically fit as you could possibly be in case it could happen again.... Again, it's not if but when. You can't control the setbacks in your MS, but you can control how fit you will be if that occurs.

Physical fitness is perceived to be a reserve, presumably one that reduces the likelihood of residual impairment following a relapse.

***Actively Avoiding Inactivity.*** One major subtheme for this theme was that of avoiding sedentary behavior and being constantly vigilant over how much sitting one engages in.

Sedentary behavior was generally discussed in negative terms, as a sort of ‘guilty pleasure’ (Amelia). The desire to avoid inactivity was often discussed in relation to impairment and disability. For example, Joyce discussed avoiding sitting in order to not become limited to only sitting while she still could get around:

I don't want to be limited to just sitting. I want to be motivated to move around and do what I need to do. For example, I love to cook and I'm starting to cook right now. It takes me a little longer to do it but I do it...I don't have to just sit here. Exercise is beneficial to me because it's helping me. What else can I say? It's helping me. If I wasn't in the exercise program there, what would I be doing? Sitting around, nothing. Oh, please, I'm active now. I'm always active doing something.

Exercise serves many purposes in opposition to sitting for Joyce. It gives her something to do instead of sitting, and it keeps her from becoming limited to sitting (e.g. from stiffness or reliance on a wheelchair).

Often the couch was the epitome of sedentariness and described a need for decompression, relaxation, represented the location where bad bouts of fatigue would relegate them and also represented a symbol for ‘unhealthy’ laziness (“I mean if all you're doing is lounging around here and there, and eating, of course you're going to lose muscle and get fat.” Leah). Justin describes the need for balance with inactivity

I'd say living healthy also goes in the mindset, or I think it could of because food is and energy that then gives you that energy to do the physical activity that then makes you feel better to do your other routine stuff. It's cyclical, and so, I think that's important. It gives you the energy to do all these other things be it family or work or play. And then having that energy to do those things instead of just sitting on the couch and not doing anything. I think it's better to do that. Not sitting on the couch. There is decompression time of which is, there could be decompression time that is inactivity, and that's fine. Again, it's in moderation, how you do it in balance.

Justin also discusses the importance of sedentary breaks for him at work where he has a desk job that is ‘extraordinarily sedentary.’ He is thus actively avoiding inactivity.

Inactivity was sometimes a result of exceeding physical capabilities when engaging in exercise and participants were very aware of this tension. For example, Dana described her uncertainty about her physical capabilities because when she's pushed herself too much with exercise, she is 'incapacitated' for several days afterward (an experience many describe especially after a relapse when their physical capabilities have been in flux.)

You know I was diagnosed last January so it's still a work in progress like trying to understand what I can do and what limit I can push myself without *wasting the rest of the week so to speak* so still kind of playing with different things that I haven't built a routine yet. I'm just kinda trying-if I can get to the gym, I am winning. Dana

Actively avoiding inactivity was also tied up in attitudes towards MS and challenging notions of pity. Shawna. says:

I think because when you move and you exercise, any kind of exercise like walking, laundry, or whatever it is I'm doing, I'm not sitting and I feel better when I move than when I'm just sitting there watching TV... I actually believe if you have MS and you're active and you keep doing things, it's better for you than if you sit there and you say, "I have MS, I can't do it."

Shawna mentioned opposition to the sentiment, "I have MS, I can't do it" on 3 separate occasions throughout the interview. Her desire to avoid inactivity is a way to challenge self-pity and to show her orientation to MS, i.e. that she 'keeps it at bay' with her exercise.

This theme was largely absent from the 4 wheelchair users in the PEMS subset (Maria, Michael, Ellen, Jessie) and the participants using a walker or wheelchair from the RELAPSE subset (Maria, Patricia). They discussed being inactive at times or activities they defined as sedentary activities, but they did not discuss avoiding sedentary behavior to the same degree. One reason this may be the case is related to the fear and uncertainty of future impairment among those with mild-moderate MS-related disability. I will explore this further in the theme related to Disability Identity.



To summarize, participants generally demonstrated that they were vigilant over their physical activity participation and over their sedentary behavior. They feel that exercise is something they *should* do to stay healthy, and to keep MS from progressing. Exercise fulfills other roles that don't carry the same disciplinary purposes, e.g. enjoyment, and I will discuss these in the theme: Exercise as medicine and/or self-care, however, generally participants discussed exercise in disciplinary terms.

**Theme 2: Exercise as Productivity and Social Engagement.** Individuals referred often to physical activity as housework, yardwork, getting out of the house/engaging with the social world, accomplishment, personal improvement, and preparation for social events. For many, productivity in the home and the outside world were both important ways of being physically active. For some individuals, productivity inside the home (e.g. housework) was in opposition to engaging in exercise. This was often attributed to a need to conserve energy, as many would not have sufficient energy to engage in housework and exercise but prioritized exercise for their health:

Yeah, the big thing is the gym, just going to the gym. That's what I've missed the most. Even before the attack, I would focus a lot of my energy on the gym. You can ask my poor wife. I don't do near as much around the house as she would probably want me to do, but that's why. I just focus on go to the gym, how much I can get done there, how much I can physically improve myself. Sam

Rebecca had a similar experience.

I'm not as able to do as much. I'm not as able to do as much around the house as I did in the past because I'm focusing on getting myself better, so I'm not doing as many things as I would around the house. I try and still pull my weight, but there's things that I just don't ... I just blow to the side because I would rather be able to get my exercise and then if I'm tired and take a nap, I'd rather do that than clean the bathroom.

For others, both productivity inside the home and activity outside the home were important. Joyce discussed her sense of pride in cooking, taking care of her home and her yard and that she felt productive when she was active in these ways but also craved ‘getting out’ and being engaged in the social world. She discussed that her scooter was key to helping her to be active in this way.

Well, I couldn't walk all the places that I go to and the scooter is a great assistant to helping me get to where I want to go. It makes me feel free. I'm not paralyzed, limited to what I can do 'cause I can get on my scooter and I can just ride for nine hours. So, yeah, it keeps me busy. It's just, you know, the social... Walmart keeps me very active. Then we go to the mall. I go the mall on average of twice a month. I love the mall... It's just communication, just actively communicating with the outside world, plus when we go there we always eat out, so that's very important to me. It keeps me active.

Although she talks about the scooter keeping her from having to walk too much (outside her capabilities), it lets her walk some, in the ways that she finds valuable. “I don't have to do a whole bunch of walking but I have to do a little walking and I know I have to walk if I use it but it's not like a whole bunch of it, just a little bit.”

Getting out of the house was very important to many participants. Elaine talks about adding in activity to her social engagements by parking farther away in the parking lot at her church where she goes to socialize.

I go to church. I park. There's a parking spot over here and I park over here and walk in to the church. The church gets me out of the house to go be with a group of ladies. I'm the youngest person that goes into this, and it's just to be with a group of ladies for an hour every Monday. But, it's just to get out of the house.

Interestingly, she notes that she is the youngest person in this group and that this group of women does not impact her decisions about physical activity but that a part of being active, to her, is being socially engaged. Elsewhere in the interview she discusses wishing for groups of friends to be active with but not relating well with people her own age (either because of her

personality or disability) that *could* be active with her and instead relates well with women much older that really *can't* be active with her. She therefore adds in some activity in the parking lot to make it “count.”

Social engagement for physical activity was particularly important for Amelia. She discussed exercise as completely social. She only enjoys the social aspect of exercise, and she is motivated by social interaction with others in this context. She is also motivated by a sense of accomplishment and productivity to engage in physical activity.

I'm not a solo exerciser. If you leave me alone I would probably sit with my book in the corner. But if I have the opportunity to go out somewhere, I'm more likely to move around, to get up and get going. Like we say get out the door and get something accomplished.

A few mentioned a need for preparing for social engagement with physical activity, in a sense building their stamina for activities that might be physically taxing. This was often coupled with discussion about researching accommodations for disabled individuals at events or locations to make sure they were preparing adequately for the experience. Sam was especially involved in this type of ‘preparing with physical activity’ behavior. He discussed that he would start walking more several weeks before social events (mentioning parent-teacher conferences, other school events for his daughter, football games and concerts, even summertime when he will spend more time at the park with his grandkids).

It's always like a preparation type of thing where I know this is coming so yeah I'm going to get exercise on that day, but if I don't prepare myself by exercising beforehand, I'm not going to last anywhere near as long... Me and my friend, every football season we go see the New Orleans Saints, so I know coming in September or next October, whatever, we're going to go and have to walk a lot. So even though that's a long time from now, with this being February, I know that I've got to continuously move around, walk around, and do my best to be prepared for that and then a month or two before that date, I really have to step it up to prepare...But then when it's not football season, me and that same friend try to go to a concert, which is the same amount of walking around and all that. So, I know that there's another event coming up that I've got to be equally prepared for so there's really no down time as far as I've got

to continue to be walking around a lot, get my endurance up as much as possible, because there's another event coming that I have no intention of missing. And you always buy the tickets way in advance so you can't bow out of it no matter what.

He discussed a particularly difficult experience where he felt he did not prepare sufficiently for the event which limited his enjoyment of the event. This reinforced in his mind his personal responsibility for being active prior to these events in order to be ready. Although he mainly spoke of his personal responsibility, he also noted the inaccessibility of many of these events and his ambivalence about his role in making the event accessible for himself (e.g. by using a different assistive device or asking for assistance). Ultimately, he believed that to be socially engaged on his own terms, he had to exercise and prepare physically, and he attributes his ability to be socially engaged to his physical activity: "It's definitely given me a huge part of my life back and I don't feel like I'm secluded in my house."

Other participants saw social engagements as opportunities for physical activity even while differentiating it from 'real' exercise. Michael mentions family social outings as one opportunity to engage socially that incorporate physical activity but that is not necessarily part of his exercise routine.

I look at going out as ... I mean, it's not anything *physical* physical, but I do look at it as a physical thing. I'll take my shower tomorrow earlier obviously, and I've got to put something on to go out. But I look at it as that kind of forces me to do something out of my normal routine, because we don't every Tuesday go out for pizza or something, so I look at it, they're keeping me on top of things.

Some went so far as to discuss productivity and getting out and about as a matter of health. Those who are more impaired seemed to discuss this more often and could reflect experiences of being limited in their participation in society or skewed views about what can or cannot count as being productive. Angela defines healthy living as follows:

Living healthy means to me, eating the right foods, getting exercise. Getting good sleep. Being sociable with people. Doing some things communally to keep you kind of

involved with other folks... I have this little thing in my head, a goal where I do three productive things a day, but I'll look up and maybe I've done one. You know, if that.

Angela discusses this lack of productivity in connection with depression often but has found online support that validates her difficulty engaging in exercise and being productive. However, she feels this sometimes can be demotivating:

Yeah, sometimes it does [make me want to be active]. Sometimes I'm like, "Alright, I don't want to sit here." 'Cause sometimes it's so depressing. It just like brings you down. It's like, "Geez, I'm not that bad." So then I get up and, "I'm okay. I'm gonna go do X."

She evaluates her ability to be productive in these instants in comparison to those of the support group and judges herself to be capable. This then motivates her to engage in activities she deems productive (such as cleaning, walking and getting out of the house).

In terms of accomplishment, many discussed feeling accomplished after completing their exercise routine for the day or getting out of the house and being active outside their home environment. Others spoke more specifically about the sense of pride and relationship to their identity and improvement as a person that came with participation in exercise. Justin, spoke extensively of his experiences with taekwondo and its role in his life:

Yes, Tae Kwon Do is a sport but the way the school in particular conducts their teaching it's much more of—it is a school. It's more of an advancement program in the person. They happen to use taekwondo to do it. And so, I was like, "Wow, this is something special." And I saw how my son was attentive to it and how it grabbed his attention and it was bringing him out of his shell. That's how we were introduced to it, and then the instructors, for a lack of a better word, tossed me a uniform and said, "Hey, I think you should do this with your son. I think you'd have fun." And that was the end of it. So fast forward three years later, we've earned our black belts; we still go to class at least twice a week if not three times a week. Those exercise sessions are an hour and fifteen minutes, hour and a half, and yeah. I'm pretty much drenched at the end of each one.

He speaks of the ways that taekwondo helps him to be engaged with his family members, with his community, that it is a source of pride, self-improvement and that this type of exercise fulfills

a very specific purpose for him, more holistically as a person than physically although that is part of the experience. Others confirm a sense of pride from daily physical activity:

It makes me happy, it just makes me happy to do it. For example, to climb 2,222 steps, I'm bragging, I have bragging rights now. "Oh, I went there and I only did just 2,222 ... " "What? You did?" "Yeah, honey, I did. I came." I have what I did and then I have MS. So give me bragging rights. So, that's it.

The sense of pride for Joyce from seemingly simple physical activity is directly related to her having MS; that MS makes 'even walking' something to be proud of.

The theme of productivity and social engagement reflects western discourses on physical fitness as fitness to be a productive and contributing member of society. This theme also reflects that the social world is built to be socially inclusive to those who are mobile and socially exclusive to those who are sick and/or disabled. Those with MS who desire to participate in the social world use exercise to prepare their bodies for social outings that are not well-suited to their needs. This ability to prepare their bodies demonstrates that individuals with MS feel some sense of control over MS, that through exercise, they can improve strength, stamina, mobility, endurance and become suited for social engagement and 'productive' endeavors.

**Theme 3: Exercise as Medicine and Self-Care.** Exercise was frequently described as important for its health benefits. Though many discussed exercise as a form of treatment for MS specifically (this was more prevalent in the RELAPSE subset, likely due to the nature of the interview questions and focus), often participants would describe particular health concerns of their own not related to MS as motivation for engaging in exercise. Anxiety and depression reduction, managing risk for diabetes and heart disease, and weight management were commonly discussed conditions that exercise was beneficial for in one way or another.

Joyce was encouraged by her doctor to engage in strenuous exercise specifically for the purpose of managing her anxiety. She talks about her experience in purely positive terms.

He tells me the benefits of it, the benefits of me exercising. The main focus is to control the anxiety and he will, for example, he'll say, "You know, if you do a little bit of strenuous exercise, that will help you with your anxiety," which turned out to be true. I am no longer on Diazepam, the medication I was taking for anxiety. I don't have to take that anymore. Because of my exercise.

This example clearly connects exercise with medicine as Joyce replaced a pharmaceutical medication with her exercise routine. Sam speaks similarly about the connection to medication:

I see it as just as important, or almost as important as my medication. It's a really big deal because if you have to take 14 pills a day and you give yourself a shot a day, this is something that's all your effort. If you can put in some effort to get better physically, that's something that's completely in your control. You're not relying on the medicine to do its job. This is something that you put some effort in, and hopefully you'll get some results from.

Sam sees exercise as his personal effort and within the realm of his control over MS. He makes a distinction between medication (outside of his effort, i.e. medicine does its job) and exercise as equally important but his own job.

There were some negative experiences of seeing exercise as medicine. This related to either a mismatch of recommendations with personal capacities, too much pressure or responsibility, or a changing self-concept with MS that could not accommodate "old self" and "new self". Jessie discusses her different experiences with 'medical' and 'therapeutic' exercise:

I can't jog. I can't even walk independently yet.... It's more of... I mean I do feel like I look for ways to challenge and to test [my abilities] but to be like 'Oh I'm going to be fit' or something was just becoming brutally frustrating and demoralizing to the point where nothing was happening.

Compare this experience of trying to be 'fit' to her experiences with yoga:

Currently I really like Kundalini Yoga and I have a Pilates for beginners tape that I keep going back to, I think that's really good. I look for mind-body connection and I am big on breathing... For me it was always the yoga that kind of got me through not being able to move. It was like ok meditate, breathe, work on this... and then to be able

to like “oh I can see that toe and move it.” Um so the yoga kind of tied me through the whole experience... I really think yoga is good for MS and part of that is just the meaning of the word 'yoga', union, and I think that it's really good to get the mind and body united.

She sees the disconnection between her mind and body after a rather serious experience with MS where she was completely unable to move. Her understanding of exercise and health had to shift in order for her to still find meaning and value in health and her body and not become overwhelmed by frustration or demoralized. She does not necessarily feel strong and capable when she's walking around, but when she is engaged in yoga, she says she does feel strong, and that it connects her mind and body where walking and other forms of exercise emphasize her incapacity.

Other participants had similar feelings about certain types of exercise being more health-related and others being for enjoyment or 'therapeutic' benefits. Dana seemed to have the most extreme opposing examples.

I have heart disease in the family, diabetes on both sides, and I'm trying to prevent myself from getting to that point. I also have very low self-esteem when it comes to my weight. I've struggled with weight my entire life and I'm a weight cyler, like I go up ten pounds two months, and the next month I'm down ten pounds. It's just a constant and a constant struggle... but, when you're so tired, even when you've gotten eight hours of sleep and you're so tired and you just can't mentally get yourself to get up and go work out, that's hard, and then, then you feel bad about yourself and then you just stress eat, then you gain more weight, then you're like "oh I really need to work out" and you just get in this whole downward snowball effect. I think MS is a lot of more mental than it is physical for me anyways.

I have a bike, so I love bike riding. I love cycling, it doesn't require me to put any like pounding weight on my legs or my back. I have a lot of back pains so, uhm, I cycle indoors and outside and when it's beautiful out... What makes me love it... having a different change of scenery, a constant change of scenery... I don't know it's just kind of freeing and it's also, I think very therapeutic to be outside. Dana

Being outside vs. inside was one of the main factors that seemed to delineate purposeful, health-improving exercise from mentally therapeutic and enjoyable exercise. Justin, who engages



in a wide variety of exercises for very different purposes, talks about the physicality of 4-wheeling outside with his kids (for him, if he breaks a sweat, it counts as physical activity).

It's just that part of almost kind of a meditative state that I find valuable, when in nature, and something I've done with my kids is go down this particular hill with a 4-wheeler and stop at the bottom of it, turn the engine off. And they all know it's quiet time, just for a second... Or sometimes if we're just hiking through. Yeah, it's that decoupling of what we are surrounded by nowadays, so it's meditative. It's therapeutic if you will.

Self-care in general was discussed separately from medical conditions. Many discussed the therapeutic benefits of exercising from a mental/emotional standpoint. The type of exercise (whether enjoyable or not, outside or inside, fun or methodical) often dictated whether the participant saw the exercise as performing a specific medical task or was 'therapeutic' in a more holistic sense. "But I don't know it's just kind of freeing and it's also, I think very therapeutic to be outside." (Dana), "Yeah, it's that decoupling of what we are surrounded by nowadays, so it's meditative. It's therapeutic if you will." (Justin).

Other individuals did find exercise simultaneously enjoyable for personal reasons and important for health.

I feel like yoga and Pilates are not only physically good for me, just mentally and emotionally it just makes me feel like I can relax. It's a good place to go to get away from reality for a while. Natalie

Many had a keen awareness of this tension, as they recognized that seeing exercise as disciplinary took away the fun and enjoyment they could experience with exercise. This in turn made participation harder for some (demotivation). Participants understand exercise to be physically and mentally beneficial but when they focus too much on the physical/health/disciplinary aspects of exercise, they miss out on the other important roles that exercise fulfills for them. Many participants achieved a good balance between these roles but

many others described a sense of dread, dislike or demotivation around exercise as discipline but a sense of enjoyment associated with ‘fun’ activities that they did for different reasons.

**Summary.** The majority of the themes related to exercise emphasize that exercise is used in disciplinary and productive ways. By being constantly vigilant over their exercise behavior, and taking care to avoid sedentary behavior participants could be productive, socially engaged and be responsible over managing their MS. These interviews also suggest that exercise is perceived to occupy many possibly contradictory roles. The participants sometimes spoke of exercise as a source of stress, something they were constantly worrying about (in terms of whether or not they were doing as much as they *should*) but also as a mental stress reliever (i.e. exercise is something that feels mentally therapeutic).

## **Section 2: Identity**

Identity emerged as a theme in several different ways. First, dueling identities seemed to underlie much of the discussion and I will therefore describe the theme, “Schism in Self and Body Awareness.” I will also describe their understandings as ‘Healthy or Unhealthy’ and their definitions of these terms. This section will set up the final section on experiencing disability and navigating an identity as disabled.

**Theme 1: Schism in Self and Body Awareness.** There were several phrases commonly used throughout the interviews that, alone, seemed minor and insignificant to the narrative being shared by participants, however, the sheer volume and consistency of certain phrasing indicated that participants experience schisms in their self-concept across a variety of dualisms. These include: my body is not me, my body is not my mind, I am not who I used to be, I miss the old me, I get myself to exercise, my MS self is not my true self, and I prepare my body with exercise

against an uncontrollable and unknowable self. The three main ways these attitudes were expressed were in descriptions of body parts acting on their own or emphasis that participant needed to get themselves to exercise (My Body is Not Me), comparisons of pre-MS self with current self (Old Self vs. New Self), and clear separation of MS from self-concept (I have MS, MS does not have me).

***My Body is Not Me.*** There were many phrases that delineated the self/subject from the body/object. These include but are not limited to: “I am my own worst enemy” (Dana), “I gotta get my rear up” (Elaine), “...just getting my butt, making myself do it... You know, so it's like I'm making myself.” (Sam). Often, this was discussed in connection with motivation. Many participants struggled with feeling motivated to exercise, but because they felt that they ‘should’ (see Constant Vigilance), they talked about ‘making themselves’ do it. Not all participants spoke in these terms or felt this way about all exercise but those who did seemed to describe bodies that were unwilling to exercise, and minds that understood the need to exercise and therefore disciplined the bodies.

Sometimes, the body was described as the subject, and body parts seemed to act on their own, such as in: “the chemicals in your brain can really screw with you” (Justin), “if I get too hot my legs go out from under me...” (Angela), “Sometimes I might go a little too far and if I do, then I pay the price for it. The fatigue will really beat me down” and “Even if I'm in really good shape, my leg's not going to allow me to run or do anything like that.” (Sam), “My right side droops and drags so I pretty much can't do anything on my own.” (Kayla), and “My legs don't really move well enough for me to swim anymore”(Maria).

One particularly clear example was shared by Carrie. She describes being in a good routine with her walking and feeling confident that her mobility was improving with her

exercises on the treadmill. She then has to confront the reality of her uncontrollable and unknowable future following a relapse:

I was walking great. I let go of the treadmill and I was walking. Relapse happens. I can't let go and my legs just don't want to stay under me. I needed to know was that forever or was it going to bounce back?" I needed him [the neurologist] to tell me that it's possible either way but this is what you need to watch for.

She describes her legs as subjects (they just don't *want* to stay under me) and the fear that she experienced not knowing if they would ever be under her control again in the same way as before.

Very few individuals were aware of the tendency towards mid-body dualism and actively worked against that. Jessie talked extensively about her experiences with Yoga as a way to repair the rift between mind and body that she experienced when her MS impairment was rather extensive. She describes this period of her life as the epitome of separateness:

There was a time when I was ready to leave my body when I was hospitalized and paralyzed from the neck down, I went ahead and signed the paperwork for no resuscitation. I didn't ask to go to hospice but it was like I don't want any resuscitation or any extra effort.

Since this experience she says that yoga "keeps me married to my body and then that is like but if you are not your body who are you?" She recognizes that her understanding of her mind and body as separate does not correspond to her understanding of self-hood (if you are not your body, who are you?) She contrasts her out of body experience to her acutely embodied experiences with yoga. Other participants confirm that exercise can actually help them to regain a sense of connectedness between mind and body or self and body among other benefits:

My exercise, I feel better, endorphins kick in and I'm a much nicer person. I'm happier. I'm more alert. I'm more aware of my surroundings... I was less depressed. I felt more in tune with my body. I lost a little weight, and I just felt more physically and mentally capable. (Angela)

Being ‘more in tune with her body’ was part of the overall improvement in her quality of life with exercise participation.

*Old Self vs. New Self.* Almost all participants described a sense of loss relative to abilities they had prior to MS in comparison with current abilities. Often these were athletic pursuits that they were involved with when they were younger. They describe their changing physical abilities as reasons why they were unable to continue engaging in certain types of exercise.

Because I can't do things like I used to do. I used to be really active. I love sports. I'd play racquetball. I used to play volleyball. (Bonnie)

For many individuals, exercise represents both a reminder of the ‘old’ self in that they feel a sense of loss over not being able to do what they used to be able to do:

In terms of inactivity, sometimes I just look at it and become depressed and I think about the old me who used to be able to just pop stuff out... [Exercise] is helping me to cope with my MS. 'Cause I'm kind of fearful of what the future is gonna bring... I used to be very athletic and I get really depressed, especially this time a year, I get really depressed about it because this is the time of year it's starting to warm up and I remember going to the gym and I used to bike and walk a lot all around the campus. (Angela)

For others, exercise was a way to ‘pretend’ to be who they used to be.

I can be physically active, and actually pretend to be a normal person like I used to be. I'm not, but because I just don't have the endurance I did, or the strength. I mean, I'm not what I used to be, and I never will be.

Here, Leah distinguishes herself from ‘normal people’ and from her old self. She clarifies normal people as having strength and endurance, characteristics that she no longer has because of MS.

She later discusses feeling ‘normal’ when she swims; her impairments fading away to the background of her experience.

One participant who did not describe this sense of loss currently (he is particularly active in a variety of ways, and exercise fulfills many diverse roles in his life) said that he felt basically

‘normal’ but would experience loss if his MS started affecting him more (Justin) but only temporarily.

Okay, well first, obviously, I would have to deal with the depression part [if my MS got worse] because I know for a fact that that’s something that I would have to deal with because I feel... So, after the initial hurdle is crossed because I don’t want to say if, I want to say when that hurdle was crossed I would still probably identify myself as healthy. Oh, okay, I’ve got this additional challenge, how do I work with it? How do I work around it? For a while there I would see people in wheelchairs... and it made me recollect from that first doctor I talked to, for the original diagnosis, not such great bedside manner. Over the phone, pretty much said, “Oh, looks like MS that can lead to blah blah blah, paralysis, para...” I mean just, boom. And if you’ve ever had a moment of you see your life flashing before your eyes, which you got an unborn son coming in, and yet, you’re being told that you could be completely incapacitated. Demoralizing is not a good definition. It’s beyond that. And it was an awful experience. And so I would see other people who had walkers or wheelchairs and things and go that could be me. And occasionally, that still pops in my head. And yeah, there’s a tinge of fear with that because that’s a major change of everything. So that’s scary. And I think dealing with that fear and dealing with that initial depression state and getting around that and going no, I just need to figure out different ways to do those things I enjoy doing, if I can, and then continue on.

His strong language surrounding his initial diagnosis and fear of paralysis and wheelchairs suggests that he highly values his mobility and his life as it is now. However, he recognizes that he may not have control over how MS affects him and so after dealing with the sense of loss he anticipates and the corresponding depression, he asserts that he would adapt and find ways to continue doing the things that are important to him. This quote exemplifies internalization of messages regarding the privatization and individualization of disability; that it would be up to him to adapt, to find ways to cope and continue participating meaningfully in society. It also exemplifies the personal tragedy view of disability; that disability and loss of mobility are tragic and that loss of mobility equates to complete incapacitation. However, he still believes that even with increased disability, he would consider himself to be healthy, therefore his definitions and understandings of part of his identity (as healthy) would remain unchanged.

*I have MS, MS does not have me.* The schism of ‘my MS self is not my true self’ was related to a sense of body awareness that many discussed as typical of an MS experience. This subtheme was not always discussed in direct relation to exercise though it is important and relevant to the aims of this research and therefore I have included it. Participants discussed the need to be aware of their bodies since MS affects everyone differently and they could not rely on information from healthcare providers necessarily or experiences from others with MS. Body awareness seemed to serve to reinforce the ambiguity of an MS experience. Therefore, another schism in identity is that of the individual MS experience as fundamentally uncertain so while someone may have a diagnosis, they still don’t know what that means for them personally.

Right now, I'm angry at the disease... Well, the first 12 years, I was okay. I really was. I had balance issues, but I couldn't walk in a line, but I could function. Then, when this happened in June, everything changed. My medication was no longer working for me... It was scary... You know, it's the unknown factor. I thought I'd be fine forever. You know what I mean? It's like, "Okay, I have this disease. I take pills. I get a shot once a week and just keep moving." It's like, "No big deal." I work in healthcare. No big deal. I got to live in denial for over a decade. Now, it's the not knowing. (Leslie)

Others discussed the way that MS controls them and dictates what they can do. Carrie discusses this in connection with her awareness of her body.

The MS pretty much decides just how much I'm going to be able to accomplish day to day. I have an idea pretty much every morning when I wake up if I'm going to be able to accomplish everything that I have set for. It directs me on how much I can accomplish. I can have the best of intentions the night before with a list of things. I want to go to the park with the kids. I want to go do this. It depends on how I wake up in the morning like how my MS starts.

MS is an outside agent even while at the same time something that she can be so keenly attuned to physically. The ambiguity of MS as a disease that people want to distance themselves from but one that they are so intimately attuned to creates a dissonance and represents a schism within the self-concept.

Others talk about pushing back against MS in a more active sense. For example, Sam discusses the balance of control:

The disease limits us in ways that are out of our control, there's always going to be things that we cannot change that we're just going to have to deal with and accept... But there's going to be a lot of things that we can change, that's what coming here and doing physical activity has shown me, that we don't have to let this disease control us as much as it will if we let it.

The interviews from the RELAPSE subset had an added emphasis on the uncontrollability of MS and that relapses increasingly alienated their bodies from their concept of themselves. Relapse highlights the lack of control of self over MS or body that individuals felt. For example, Amanda discusses coming out of a relapse and starting to feel better then wanting to start exercising again to prepare for the uncertain future:

That was another thing I knew that if it was just my arm and I could compensate that I wanted to keep exercising it and in case it got worse and I couldn't later. It's like take advantage of how good it is now because it could get worse later. I could wake up tomorrow and I can't even lift my left foot.

Patricia had a similar experience but spoke of control in similar ways to Sam above. Exercise becomes a way to regain some control, though it is limited and does not control the MS, rather, prepares the body for the MS.

I think that the main thing with exercise is like if a relapse is going to happen that's out of your control. You can't determine that but you can control how physically fit you are. Otherwise, you could be ... so I think it's the best thing is to be as physically fit as you could possibly be in case it could happen again... Again, it's not when. You can't control the setbacks in your MS but you can control how fit you will be if that occurs.  
Patricia

However, as I have previously reported (see chapter 3), many felt that they could exacerbate their MS through exercise as well, creating ambiguity over its role in relation to MS. Sam discussed one of his relapses in this way:

Because it's scary, if you start to become physically active and you start to do things and then an attack comes, you really have to step back. Because maybe it didn't have



anything to do with me being physically active, maybe it would've happened anyways. It's just in my mind, it's like I just did that to myself.

Maria described a similar experience though she recognizes that her hesitancy is sometimes perceived as laziness. "It's not just laziness, it's also the fear of ... The last time I did that [over exercised], 1 step forward, 3 steps back. I need to deal with that hesitancy.

**Theme 2: Healthy or Unhealthy?** There was wide variation between participants in how they identified as either healthy or unhealthy and why. In general, participants fell into two groups, those who did not associate having MS with being unhealthy (i.e. a diagnosis of MS does not mean I am sick) and those who did associate having MS with being unhealthy (i.e. I have MS, therefore I am unhealthy.) Defining characteristics of being unhealthy were, increased connectedness to the doctor, healthcare system, medication and feeling immunocompromised such as in the case of Leah:

Well, after the IV steroids I will go on the course of the pill form of steroids, Prednisone. And I will do that for, typically, on average about three weeks. Three and a half weeks. So, after that my immune system is just really, really crappy. Once I get a cold, or sick it seems like I no sooner get over one than I'm down with the next one, and the same thing. And it'll just go on for months so once I get down, I stay down. So, I get hit by the episodes pretty consistently because I'm so far down.

A few participants were keenly aware that they did not know how to define themselves on a scale of health. Sickness, illness, disease and disability all seemed separate but related to these individuals. In this passage, Amelia tries to define health:

Definition of health, yeah okay I'm not sick. That's real good. It's like doing the forms of a lot of these studies that will say your overall health. Well okay, I'm fine. I am pretty healthy. I don't get sick very often, but I have MS. So what do you want to do? Which one do you want to say. Okay, I have MS and osteoporosis, but I don't get sick very often. So where am I on your scale from 1 to 10 in terms of health? I don't know. It depends on how you define it... I'm in the middle. I have some chronic problems, a couple weeks ago I was sick, but it doesn't happen very often...If you are up and moving around and are able to do the things you want to do, then you are in fairly good

health. If something is keeping you from doing those things, then it needs to be addressed.

She categorizes acute sickness, limitations and certain habits as unhealthy while her chronic conditions don't necessarily mean she is unhealthy. The delineation becomes tricky when the chronic condition is limiting her ability to do the things she wants to do. She places value on being able to do what she wants and sees this as related to health. Later she emphasizes that exercise is useful for managing her chronic condition and keeps her doing the things that are important to her. In this way exercise manages the disease, which manages her disability/impairment, which contributes to her overall health.

The line between illness and disability was especially tenuous as described by Jessie.

I will say that and on an up-note, I just had my six-month review with my neurologist and he is very delighted and really was like "you know of all the treatments and medications you've had, your immune system has now been rebooted and you should not fear another flare" It's like how often do you hear that? Never. No, it is, it's like ok so I'm healed but I'm still disabled; but he also then was like "The more you exercise is the way that's going to reconnect how things are accessed in your brain."

She makes a distinction between healing and disability based on the information from her doctor regarding the state of her MS. She takes what he says as signifying healing of her immune system (damaged by MS) but that her disability remains. In this moment, the connection between illness (MS) and disability disappears but her doctor then tells her that exercise is the way to overcome the disability that remains.

For some participants, MS challenged their identity and self-perceptions as "a healthy person." For instance, Natalie, who is newly diagnosed, discussed her desperation over her new diagnosis.

Oh my gosh, it affected my body image. I didn't want to go and be around people. I just didn't feel good about myself. I felt kind of like you lost part of yourself; like your identity was just taken away from you. You just have to cope with it.... I have my days

where I just want to break down and cry. Why is it that I have this? Just kind of confused as far as why do I have this? I thought I was healthy.

Those who are newly diagnosed seemed more likely to associate MS with unhealthy whereas those who had a longer history with MS considered themselves healthy. Their understanding of MS seems to transform from a sickness to a condition.

**Summary.** Participants described various dualisms within their self-concepts. These included feeling a lack of control over certain body parts and attitudes of ‘mind over matter’ (I have to get myself to exercise) conveying feeling a mind/body separation. They also described their sense of loss over their ‘old’ selves and old abilities and a need to separate themselves from MS. Furthermore, many acknowledged the difficulty in categorizing themselves as healthy or unhealthy. Being ‘healthy’ means exercising and eating right, not having acute sicknesses (like colds) too frequently for some but for others, having MS means they are unhealthy. This is especially true for those who are highly tethered to the medical realm (copious medications, frequent visits to the doctor, compromised immune function etc.). Disability does not necessarily equate to unhealthy though some experience both simultaneously.

### **Section 3: Disability and Disability Identity**

The final section related to disability will outline the participants’ experiences with ableism in connection to PA participation, their decisions about assistive devices and the meanings they ascribe to different assistive devices, and finally, I will conclude with a section describing evidence of disability identity and its relation to exercise.

**Theme 1: Ableism.** Participants in the more severe categories of impairment experienced and discussed a variety of instances of inaccessibility and overt ableism in connection with their decisions about physical activity. Most mentioned both facilitating examples, e.g. where a gym,

park or place they chose to be active was accessible and met their needs and examples of inaccessibility where participants were either limited or frustrated by the opportunities available or state of the facilities. Furthermore, many discussed over ableism in social interactions (i.e. psycho-emotional disablism). For those who were in the mild category of disability, a few still mentioned accessibility but not as a barrier to participation in exercise. Their experiences seemed to be more reflective of internalized ableism and ableism of family members. Extensive previous research has outlined the ways that individuals experience inaccessibility within the context of exercise (for example: ( Kayes, McPherson, Taylor, Schlueter, & Kolt, 2011; Learmonth & Motl, 2015; Richardson et al., 2016; Shields, Synnot, & Barr, 2012)) and therefore I will not give further discussion to that topic here as these interviews confirmed this previous research. The following section will discuss overt and internalized ableism in the context of physical activity and MS.

***Disbelief.*** Many participants discussed their experiences with disbelief regarding their symptoms or abilities. Most often, this occurred with family members and close friends. There were three types of disbelief shared: disbelief in a person's *inability* to engage in exercise (come on, you can do it), disbelief in a person's ability to exercise at a higher level, and disbelief in MS symptoms because of a person's ability to exercise.

A few participants talked about being encouraged to exercise more by friends or family members even when they themselves knew they were not capable. For instance, Joyce talks about disbelief in her stamina:

Let's start with my husband. He tells me, "Yes, and it helps you, it gets the stiffness out of your body in certain places and you move around and you need to do this." Yeah, he gives me a lecture about that. My other family, "Yeah, oh, I love to exercise. You need to walk more." "I'm not getting ready to walk around a park like you, are you crazy? Girl, I make five to six steps and you'll see me on my scooter." So, they always trying

to encourage me to do ... And I tell them, "I can't do that." "Yes, you can." "No, I cannot. I'm not gonna even try it." I can't walk that far, I'm barely able to walk 25 feet.

Elaine has a similar experience related to her decisions to push-mow her yard as a form of physical activity that she enjoys.

I do the part that the house sits on one day and the other part that the house doesn't sit on the other day because I can't do it all in one day. My husband gets very frustrated with me. He's like "you should do it all in one day" and I said, "I can't, and it wears me out." He's like "Oh you can!" I say "No I am tired" ... I think he doesn't understand how I feel. And I try to explain to him and he blows me off. He gets on the rider and does it and yea I could probably get on the rider and do that but that's not physical activity to me. I want to get out there and push mow. I said "yeah it takes me longer to push mow it but I'm... if I get on the rider that's not activity. That's not physical to me. If I push mow, it's more beneficial to me than if I would get on that rider. And he doesn't understand that...

These experiences were particularly frustrating for participants as they were engaging in the amount and type of exercise that was suitable and appropriate for them but in these interactions, the exercise is deemed unworthy, unsuitable, and insufficient and the person feels perceived as not pushing themselves hard enough. This invalidates their experience with MS as well as their efforts to engage in physical activity.

For a few, engaging in exercise had the opposite effect: it led to disbelief about the person's experience with MS. This can be particularly challenging as the person then has to choose whether to exercise enough to convey how their MS makes them feel or live with being disbelieved regarding their experience with MS.

I just feel like I'm limiting myself because of what other people are saying to me about my MS. You know my leg is really stiff when I sit down for a while and my mom's like, "Well you got your legs, you know, and you have these migraines," and it's like, "You don't understand. This [exercise] helps energize me!" ... My family, I think they support me, but they don't because they think if they see me walking to town, which is like a mile up and a mile back, "Oh well then ..." "She's fine. You know, what's she talking about. She's just making this stuff up." Angela

This participant discusses the lack of acceptance of other aspects of her identity by her family as well, in particular her identity as lesbian. In order to have other parts of her identity validated (MS), she may be 'limiting' herself in order to avoid this disbelief. What she says she will lose are the energizing benefits of exercise.

Lastly, Sam discussed his frustration at not being perceived as athletic in gym environments because of his use of a cane. He spoke at length about his previous 'gym rat' identity and learning to be OK with his new physical abilities. He describes feeling out of place with two different types of people at the gym now:

The YMCA is one of the things that really helps me be more physically active. I'll go there and I'll exercise... It does kind of have a flip side to it as well in that I'll go there and I'm working with a cane, and sometimes I can kind of see the muscle heads, I'll say, a little bit annoyed that I'm kind of in the way or I'm working on a machine or I'm doing some free weights. That is kind of cramping their style... But then at the same time, there was one time I was doing arm curls on the preacher bench and a kid came up, 13, 14 years old, and asked me if I needed any help putting on my weights. Which yeah, that was very nice of him, but at the same time really annoyed me. I said no, I'm good thank you, I hope I didn't come across as annoyed to him because at the same time when you're disabled and you're doing something and people will sometimes come up wanting to help you, and it's really the last thing you want. Sam

He then acknowledges that he probably used to be the same way as the 'muscle heads' when he was younger and didn't want to be the guy slowing everyone down. He struggles to reconcile these two versions of himself (see Old Self vs New Self above) in order to find his place at 'the gym' and use those facilities to reach his goals. He wants people to recognize that he belongs there and is able to 'get a workout' even though he uses a cane and may move more slowly, however, he is not naïve as to the sentiment as it was once part of his gym identity.

**Theme 2: Assistive Device Decisions.** Participants discussed their use and understandings of assistive devices frequently in conjunction with their experiences with physical activity. Several meanings regarding certain assistive devices seemed to carry

throughout the interviews. Many of the participants are full-time cane users but discussed occasions where they choose different assistive devices for specific purposes. The participants discuss making conscious decisions about which assistive device to use based on their specific needs and their perceptions of how they will be seen/perceived in the social world.

For several, the use of any assistive device was emotionally difficult. They believed that assistive devices were exclusively made for older adults and this did not fit with their self-concept as young adults. For example, Kayla said “I’m not fond of using my walker or my cane. I would rather fall and get back up rather than use that stuff and look like an old person.” However, even older adults with MS had difficulty accepting the presence of assistive devices in their self-concept.

My activity is different than someone else's activity. There have been people that were diagnosed with multiple sclerosis and their body functions just ... They end up in a wheelchair. I do have a walker. I try not to use it. I try not to have to be dependent on it... to tell you the truth I don't want to end up in a wheelchair...I don't want to be dependent upon a wheelchair. I don't want to be dependent upon the walker. I know I can't move around because I used to be able to walk wherever. I start one place and just walk 2 to 3 blocks or anything like that walk around the block, or something like that.  
(Bonnie)

Bonnie emphasizes that her discomfort around assistive devices is related to *dependence*. She has a walker but avoids using it in order to avoid *dependence* on the walker and engages in exercise in order to stay independent. Other participants spoke similarly about the feelings of using assistive devices that are more ‘advanced’ than the ones they use on a regular basis. Some spoke about using the more advanced assistive devices to make things easier for themselves or others despite their feelings about the meaning of those assistive devices, for example:

If I have an issue, like a seizure, I can't control it, so then my wife's got to walk alongside me, try to keep me, and then do that, so it's easier sometimes to, even though it's more physical, for her to take the wheelchair than the scooter. That's what we do.  
(Michael)

He takes into consideration what will be easier for his wife when making his assistive device decisions. Patricia and Amelia also described using wheelchairs when it is convenient for their family members, more related to age and less to MS. Sam, on the other hand, protects his self-concept and avoids using a walker or rollator even when he knows it will be more difficult:

Even though I knew full well I was going to, by using the cane it was going to be a lot harder, a lot more painful. But I don't know, I guess it's harder to take that step towards recognizing you're more disabled than it is to just grin and bear it, I suppose you'd say.

Sam had the most discussion regarding assistive device decisions. He described crutches as signifying more temporary impairment but a walker, rollator or wheelchair represented permanent disability. He uses a cane full-time which was a difficult transition in and of itself. However, several experiences made him aware of perceptions of cane users that did not represent him. For example, at a football game, he describes being ignored by the transportation for disabled individuals. He realizes that he was ignored because people did not see him as needing the kind of assistance that he needed (transportation). He describes:

What I ran into was that, I'm a guy walking with a cane. So, and I can kind of understand their mentality, I would've thought the same way, well he's walking with a cane, he's fine, he can walk as far as another person he just needs a cane.

His fatigue was the impairment that was concerning to him at this moment, not his mobility and he recognizes that he probably would have understood someone in his situation similarly before having MS. The understandings of who needs/uses certain assistive devices do not fit with the experience of having MS. Many wheelchair users with MS in this group could walk, and would walk in certain situations (at home for example where maneuvering a wheelchair was too difficult), however, generally, we perceive full-time wheelchair users to be paraplegic and incapable of using their legs. Because of the ambiguity of ability, persons with MS are faced with *decisions* about assistive devices instead of necessity per se.



For those who are using a wheelchair full-time, physical activity helps them to move backwards away from full-time wheelchair use. For example, Maria has a specific activity in mind when discussing her rehabilitative goals with exercise.

Today, I was able to walk almost as far as I would have to walk to be able to go down to eat at the cafeteria area. I may start walking more with it. Because my goal is able to walk far enough so I can leave my apartment and go down to where people eat and then sit and eat and then go back up to my apartment with the walker and not be using my wheelchair as much.

Generally, participants were ambivalent towards assistive devices; they were helpful and allowed participation in meaningful activities, but they also represented parts of their self-concept that were undesirable. This represents aspects of internalized attitudes about disability and assistive devices. Participants make conscious decisions about which assistive device to use based on their specific needs and their perceptions of how they will be seen/perceived in the social world.

**Theme 3: Disability Identity.** This theme had the biggest variation between participants. The purposes of the interview subsets were not to understand how participants identified as disabled or not, however, this topic was an important part of the discussion for almost all participants. The participants involved complicate Mia Mingus' concept of descriptively and politically disabled in that some participants do not have the lived experience of disability. Returning briefly to Mingus' definition of who 'counts' as descriptively disabled: "They may not talk about ableism, discrimination or even call themselves "disabled," but they know what it feels like to use a wheelchair, experience chronic pain, have people stare at you, be institutionalized, walk with a brace, be isolated, etc." (Mingus, 2011). However, for several of the participants in this study, they do not experience chronic pain, mobility problems, walk with a cane, have people stare at them or feel isolated all the time or even at all. For many of these

participants, the afore-mentioned experiences are transient, looming in the future, avoidable (maybe with exercise and management), or have not happened at all. Some are still at the point of negotiating an identity as descriptively disabled and are far from gaining an understanding of disability in political terms or in terms of identity.

Because of the heterogeneity of experiences with disability both descriptively and politically, this theme will be structured differently than the previous themes. I have separated the participants into three categories of identification with disability: Ambiguous descriptive disability/ fearing descriptive disability; Clear descriptive disability but working to reverse; and Accepting descriptive disability and moving towards political disability.

***Ambiguous descriptive disability/fearing descriptive disability.*** This group was comprised of all individuals in the ‘mild’ impairment category, as well as 2 from the moderate impairment category and 3 from the severe impairment category. The defining feature of this largest group of participants is the ambiguity of experiencing disability. For these individuals, disability as a lived experience comes and goes. They have choices about assistive device use (they can use a cane, walker or wheelchair when they think they need it but sometimes choose to hold onto other people or go without and can manage). When they are experiencing ‘descriptive disability’ they may not necessarily identify as disabled even during those periods of time-exacerbations/relapses of symptoms are temporary and are described and experienced more as sickness than as disability. However, during those periods of time, individuals fear that state becoming permanent (as if the permanence transforms sickness into disability). Almost all individuals in this category fear the wheelchair and use it as the ultimate symbol of disability. Many are passing because relapses are infrequent, those moments are not representative of their true self. Several have unclear definitions of healthy and unhealthy and do not know whether to classify MS as an

illness or condition or something else. This was especially true for those newly diagnosed such as Natalie:

My legs just don't seem to be as strong as before. I don't know if that's because I know I have the disease or if it's just in my head. I don't know. Just typically my legs have becoming weaker so I've been really trying to do a lot more squats, riding my bike, uphill things, so...

There are a few whose experience differs in regards to fearing descriptive disability.

Shawna does experience ambiguous descriptive disability which she manages with her avid yoga routine. She does not seem to fear future disability or work to actively avoid it with her yoga, even though she attributes her 'good fortune' with MS to her yoga practice. She is older and her long and predictable (by her standards) history with MS could explain why she does not seem to describe the same fear that others in this group do.

I don't think a lot about the future because I know that as I get older, it's going to get a little bit more difficult, but I'm not going to give up. I'm going to keep doing what I'm doing and just keep trying. Then when I get to that point, then I'll think about it. Right now I don't want to. Shawna

Carrie seems to fluctuate more frequently, her ambiguity more difficult because of the sharper fluctuations day to day. She describes a higher awareness of their bodies and engage in body checks to see what their capacities for the day are. Amanda describes how relapses are moments of increased uncertainty regarding her future with descriptive disability:

Since I've had MS for years now, I know that I'm able to usually work around things no matter what the relapse will do, ones I've had so far, but I've been able to compensate or wait it out sometimes. Take steroids or something, and once it gets better than I can get back to normal. It affects me more as in mentally sometimes because I don't know if it's going to be permanent. I don't know if it's always going to get better.

The physical impairment to her is not as challenging as the fear of permanence. Even though her experience has been episodic to this point, she knows that it may not stay that way, that she might be left with residual impairment after a relapse and not get back to 'normal.' A tendency

towards seeing the self as ‘normal’ with exacerbations and ‘bad days’ as out of the ordinary keep these individuals from seeing themselves as descriptively disabled, indeed, according to Mingus’ description, are they? They have the lived experience of disability sometimes, and they feel that they do exert some control over that experience through engaging in exercise and other MS management therapies. Indeed, some indicate that their healthcare providers encouraged this thinking:

Physical activity, since I was told I have MS, is important to me because if I don’t stay physical, that means I could possibly end up in a wheelchair and it may end up that way, because the MS may advance anyway. We don’t know, but as long as I feel that as long as I continue to stay active, my prayer is that it won’t advance. (Elaine)

Elaine acknowledges that she MS may progress with or without exercise but clearly associates inactivity with increased impairment. She does ‘her part’ and hopes it is enough to prevent future disability.

*Clear descriptive disability/fearing and reversing descriptive disability.* These individuals acknowledge freely that they experience disability. Most individuals in this group are in the ‘severe’ impairment category with one from the moderate impairment category. From a descriptive disability perspective, their experience as descriptively disabled is much less ambiguous on a day to day basis (their symptoms are fluctuating but above a critical level of disability) however, they still see this location as negotiable. They are full-time assistive device users (canes and/or walkers and/or wheelchairs) and most even call themselves disabled at some point during the interview. The ambiguity in this group lies in the believed impermanence of their disability status and hope to be able to reduce impairments (with MS management and self-care behaviors including exercise) in order to no longer identify as disabled. Cane-users fear the wheelchair much as the first group does and wheelchair-users work to reverse dependence upon the wheelchair with exercise and physical therapy.

Being healthy is huge, I know way back before the MS came I liked going to the gym and playing basketball and it was a main part of my life. And then the MS came along and buffered that, definitely limited it. So, and *especially now that I'm to the point of being disabled, the more I can do to become not disabled, the better*. So being healthy of course is a major part of that, and for me it's the exercise and the activity... If the day came along to where MS was actually cured, I would definitely go back to being how I used to be, as far as I could, I'm not 21 anymore I'm 44, so I know that those days are gone regardless. But yeah, it's very important, I do as much as I can... (Sam)

Sam does not indicate that he is in any way interested in adopting a political identity as disabled.

He acknowledges clearly that he is disabled but he asserts that he is doing everything he can to 'become not disabled' through exercise. He locates the responsibility for improving his experience with MS solely as individual, even though in other instances he talks about the frustration he feels when events he attends are inaccessible. For him, previous experiences exercising with MS (that greatly improved his mobility, reduced his fatigue, and improved his overall well-being) motivate him to continue to exercise as he hopes to continue to experience those improvements.

Yeah, and for me it's essential to just not lose anything more, and maybe even get a little bit better. When I first got involved in the exercise program here, my improvements were so unbelievably good. That's when I got to the point well, I've got to keep doing this. I have no expectations of ever getting back to 100%, but if I can maintain or even get a little bit better, then it's absolutely essential to do on a weekly basis.

This attitude reflects the first theme, Constant Vigilance, in his use of the phrase "absolutely essential." By being vigilant over exercise behavior, the participants in these first two groups hope to reduce disability and prevent future disability. Because MS is so uncertain, they believe they must be constantly vigilant because increased symptoms or relapses could happen at any time. They must always be prepared.

Tammy hopes to become involved with disabled sports groups and clearly self-identifies as disabled, however, she recognizes there are aspects of her disability experience that she

wishes were different. She uses physical therapy and physical activity to try and build up her stamina in order to rejoin the social world she misses:

I was obviously having trouble with my left leg and to try and get it strengthened again—that's what physical therapy is doing. They're helping me and it's stiff like when we did a couple tests it was stiff, the left leg and it's better actually than it was. It's frustrating. I don't know... all of it is just very frustrating because of how I was in the past and then how I am now. I would like to work, you know. I would like to do those things and socialize. I'm a social bee and I miss it. So, it's just frustrating.

So, while elsewhere she challenges social norms and monolithic understandings of disability, in her day to day experience, reducing her impairment through exercise helps her to recapture her social participation. She demonstrates the internalization of an individual orientation to disability; that it is her responsibility to overcome disability and she uses exercise to do so.

*Accepting descriptive disability/gaining identity as politically disabled.* This group indicated some aspects of acceptance of their situation as descriptively disabled (accepted their impairments) and showed signs of identification with political disability. This group of individuals is more accepting of their disability status. These individuals were all in the severe category of impairment. They are not as conflicted as the second groups of individuals and are more aware of ableism and inaccessibility. They are not necessarily politically disabled according to Mingus' definition, but they acknowledge ambivalence regarding these topics (e.g. I understand why many places are still inaccessible, but it is still frustrating and difficult for me to get around).

Angela describes her acceptance of her impairments in opposition to her family members' and her frustration regarding their emphasis on cure. She describes their unsolicited advice:

Yeah, they still have this image and I've tried to tell everybody, don't send me stuff about cures or new trials or this will help you or any diets and they still, it's like, Rrrrrrrr. You know, I don't say anything and that's part of what brings a lot of stress. I

guess I should just let go and say, "Look, I know you're trying to be helpful, but this is not helpful." ...Some of them will say that, "You probably already know this but ..." there'll be something on CBS news and it's been going on for 18 months to three years. And they're like, "Oh I saw this on the news." And it's like, "Ohhh, if you only knew. I know about this trial. I know about the results. I know about the sample size." It's like, "Come on." My mother, everybody's that way.

She does not reject her experience with her medical care, she values the ways that it helps her, and also values physical activity as a way to improve her overall mood and quality of life even if it does not change much regarding her impairments/disability. However, the constant barrage of information from family members and friends regarding cures and treatments for MS frustrates her.

Ellen sees problems with accessibility in many places. These are the main barriers for her physical activity. She personally adapts to her surroundings but also makes conscious decisions about where to go. For example, she discusses a particular restaurant that she will not go to because it refuses to remodel and become accessible:

I don't usually avoid things, but it makes it harder, and I, you know, I, you know me I just do what I gotta do. I know that going down to that coffee house down the road here that one time I got caught and it ended up breaking one of my foot rests on there so that's kind of just hard sometimes. I get a little irritated. I can't go to like the \*\*\* Cafe. I don't want to go there because it's really steep stairs and I refuse, I have to. I think he should... He's not gonna remodel because he doesn't have to. If he remodels, he'll have to put handicap accessible and he won't do that so I kind of avoid that because of that so.

One participant spoke very positively about the shift to becoming disabled in terms no other participant described. The onset of her MS was quite severe, and she described her initial reaction to her new diagnosis and new perspective on disability:

...what I really became captivated by was India and the idea of reincarnation and that we are all part of the same colorful pattern and when I had the exacerbation and woke up and was paralyzed from the neck down, I realized that wow, reincarnation happens even when you're still alive... I'd like to think the gift of my disability is that it allows people to do nice things for me. And that it gives them some way to feel better about themselves. I've been helped by what I know are like gang teenagers or rustabout kind

of types. I mean that normally in the past, I would walk back to the other side of the street. Instead, it's like, "Do you need help?" Okay and then being helped across.

She finds value in a new type of connection to her community, it helps her to cope with the more challenging aspects of living with MS. She simultaneously is more aware of inaccessibility and frustrated by assumptions of her incapacity (e.g. people trying to help her walk when she's walking fine on her own). She also experiences a great deal of pain regarding her identity as disabled in relation to her husband and in her roles as a woman and wife:

For me the part of disability that was really hard of like "what am I as a woman? What am I as a wife? Put me on the shelf" I was just very uncomfortable so for me yes physical activity is a way for me to stay partnered with my husband.

So, although other parts of experiencing disability came 'naturally' to her given her worldview, this particular aspect is very challenging for her. Instead of using exercise and physical activity to reverse her physical condition, she says that physical activity keeps her 'partnered' to her husband, a connection that she describes as her interaction with the world.

Two clear outliers in this group were Leah and Kayla. Leah actively identifies as disabled, does not seem to accept or feel a sense of positive affiliation with disability, misses feeling 'normal', but is also actively questioning definitions of disability, who counts as disabled and who does not, and is aware of ableism and frustrated with a lack of access. The clearest example of this comes as she discusses interactions she has with others about her car.

Nice car. Nice two door, technically it is a sports car, it's a very nice-looking car. But we have the handicap placard, and we pull into a parking place and you can just see their face, especially the older generation. "You're not old, you're not allowed to park there." You can just see it in their faces. And some of them have actually come up, before we get out of the car, and are just, "You're not allowed to park here." And because I'm young, I'm not allowed to be handicap. It's very much the impression I've gotten from the words, the looks. I mean I've had people purposely shove their carts heavy into my car, while I'm watching, because I'm not supposed to be parked there. I'm not handicap. Despite the fact that I get out of the car, and then I'll get out of the car with the cane and you can just see their faces change. It's just one of those because I'm not old, I'm not allowed to be broken.



She recognizes the fallacy of conventional definitions of disability and challenges the assumptions surrounding questions of who is disabled. She explains that this attitude is likely a result of her upbringing:

One of the things that is unique with me is I've grown up in auto racing. So, I've been there when people have gotten hurt. I've seen the bad wrecks. I've seen the come backs. I've seen people of all ages being down and very physically damaged for however long it took them to get back up. So, to me handicap doesn't have an age. Where it seems like most everybody seems to think it has an age, and that's old.

So, although she herself does not feel positively about her impairments, she identifies as sick and recognizes the highly medicalized life she leads, she challenges notions of disability that are exclusionary to her experience.

Similarly, Kayla does not have a positive identity related to MS, she does not want MS to define her and she also does not want others to treat her as inferior because of MS.

When I do anything like going back to school, my motivation was my son and my mother. Now since my mother's gone, my motivation is him. I have to keep focused and let him know that just because we have an illness, that we cannot let that control what we're doing. We have to stand tall for ourselves and each other to let each other know that just because we have an illness doesn't mean that we're not equal to anybody else who's walking around.

Her role as a single mother trying to go back to school to care for her son seems to feed her insistence to not let MS control her and to stay out of a wheelchair as she describes forcefully in her interview. She recognizes the systemic inequality that exists for disabled individuals and actively avoids having a reason to experience that inequality (by letting MS control her).

Interestingly, though she emphatically affirms the equality of people with illness to other people, she does so by comparing them to 'anybody else who's *walking* around.' Even as she insists upon equality, in her mind, there is a line she will not cross, and that is immobility.

**Summary.** Participants who experience disability in less ambiguous ways seemed more likely to begin developing a critical understanding of questions of access, ableism and who is/is not disabled. They mostly engage in exercise for different reasons (i.e. not to reverse disability) such as for enjoyment purposes, social connection, as part of their routine or their lifestyle. However, exercise participation is also a venue in which they experience ableism and inaccessibility. For those more recently diagnosed or with milder impairment, descriptive disability was still ambiguous. Exercise is used as a way to navigate the experience as descriptively disabled (i.e. preventing or removing impairment).

**Table 3. Summary of IPA themes**

<b>Category</b>	<b>Theme</b>	<b>Summary</b>	<b>Exemplary Quotes</b>
Exercise	Constant Vigilance, I should exercise	Participants feel that exercising to promote health and manage MS is their responsibility. They feel guilt for not exercising. They think about exercise often and see opportunities for exercise everywhere.	I should be going 3 or 4 times a week. I just wish there was a way to do it every day... It'd be nice to have something at home to where I can even just sit there and watch TV bicycling or something. (Ellen)
		<p><b>Subthemes</b></p> <p>-Actively Avoiding Inactivity: Sedentary behavior is understood as something to be actively avoided. Inactivity is associated with laziness, depression and is also something to be feared (increased disability would lead to inactivity presumably).</p>	<p>It's a constant struggle and I think a lot of people have that, am I feeling up to working out after work today? It's a constant, I'm constantly thinking about it and it stinks, but if I don't think about it, then it's-- yes, I'm less stressed but then later on I'll be more stressed because I wasn't thinking about it. (Dana)</p> <p>Getting away from technology and not letting it let me just lay on the bed or sit on the couch or what have you. Minimizing the amount of time I spend with that, I'm better off. (Justin)</p>
	Productivity and social engagement	Being active is being out and about in the world, socializing, being productive, and doing things outside of the home. By being active/exercising participants feel productive. Productivity is important in both the home and social world. This includes exercise for achievement, improvement, investing in self, transforming self, setting and achieving goals.	<p>Then it helps me socialize. I can socialize even more in a different environment. Then I feel good. (Joyce)</p> <p>I feel, if I've walked 10,000 steps a day that I have accomplished what I want every day. (Elaine)</p> <p>I'm not a solo exerciser. If you leave me alone I would probably sit with my book in the corner. But if I have the opportunity to go out somewhere, I'm more likely to move around, to get up and get going. Like we say get out the door and get something accomplished. (Amelia)</p>

**Table 3 (Cont.)**

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Exercise as Medicine and/or Self- Care	Exercise is described as a way to manage symptoms of MS and other health concerns. Part of being healthy is engaging in exercise. Exercise is also described as a form of mental and emotional self-care.	My goal right now with exercising is to build my strength, especially my left leg, and maybe get to the point where I can walk the two miles a day. (Tammy)  I feel like it's not only physically good for me, just mentally and emotionally it just makes me feel like I can relax. It's a good place to go to get away from reality for a while. (Natalie)
Identity	<p data-bbox="354 636 509 777">Schism in Self and Body Awareness</p> <p data-bbox="542 636 850 888">Self-concepts are dualistic and reflect mind/body separation. Exercise is an activity that throws this separation into sharper contrast.</p> <p data-bbox="542 930 695 961"><b>Subthemes</b></p> <p data-bbox="542 968 850 1251">-My body is not me: Body parts act on their own, body is outside of the control of the mind, the self that wants to exercise disciplines the body that does not want to exercise.</p> <p data-bbox="542 1262 867 1545">-Old self vs new self: There is a sense of loss for old capacities and old self-concepts related to exercise and athletic endeavors. The new (MS) self cannot do what it used to do.</p> <p data-bbox="542 1556 867 1799">-I have MS, MS does not have me: Participants use strong language to separate themselves from MS; there is a balance of control between self and MS.</p>	Basketball is one of the things I like but if I get too hot my legs go out from under me. (Angela)  Especially the swimming where I get to go outside and be physically active in a way that I never get hot. It's an outdoor pool, it's pretty chilly, which I love. I can be physically active, and actually pretend to be a normal person like I used to be. I'm not, but because I just don't have the endurance I did, or the strength. I mean, I'm not what I used to be, and I never will be. The fact is I can't feel my feet, I can't feel my hands. A lot of times I can't feel my right leg at all. (Leah)  When I have a flare up I'm usually on a walker or a scooter at school. My right side droops and drags so I pretty much can't do anything on my own. Over the course of the 11 years, the MS has changed a lot, so I don't know what's going to happen now, where I used to be able to say this is going to happen, this is going to happen. I don't know what's going to happen now. (Kayla)

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**Table 3 (Cont.)**

Healthy or Unhealthy?	The ambiguity of MS as an illness, disease, form of disability was apparent. MS is a middle ground between healthy and unhealthy for some, in no way is associated with being unhealthy for others and is entirely tied up in medicine (unhealthy) for others.	Definition of health, yeah okay I'm not sick. That's real good. It's like doing the forms of a lot of these studies that will say your overall health. Well okay, I'm fine. I am pretty healthy. I don't get sick very often, but I have MS. So, what do you want to do? Which one do you want to say. Okay, I have MS and osteoporosis, but I don't get sick very often. So where am I on your scale from 1 to 10 in terms of health. I don't know. It depends on how you define it. (Amelia)
Disability	Ableism  Descriptions of attitudes, interactions, and conversations that are negative in nature and that reinforce negative perceptions of disability or disabled people. Instances where participants encounter compulsory ablebodiedness (whether internally or externally). This includes instances where participants challenge current understandings of disability.	The YMCA is one of the things that really helps me be more physically active. I'll go there, and I'll exercise, of course that's a good motivator, that's a good way of staying physically active. It does kind of have a flip side to it as well in that I'll go there and I'm working with a cane, and sometimes I can kind of see the muscle heads, I'll say, a little bit annoyed that I'm kind of in the way or I'm working on a machine or I'm doing some free weights. That is kind of cramping their style. (Sam)  [For my family], I don't go fast enough when I wheel myself so a lot of times they insist on pushing me. That. I don't like that at all because I've got the manual wheelchair so that I can push myself, but I'm slow. (Maria)
	Assistive Device Decisions  Because MS impairment fluctuates and most do not have total mobility loss, assistive devices are seen as different options with different meanings. Canes are used often as a way to maintain PA in social	At vacation, I'll be in the chair a lot more, and at the airport. My wife wants me in the chair because it's so crowded, and I've gotten pushed around, and I've gotten knocked down, so we have to use the chair there. So, I've got it in case I need it, but it's the last resort. She's got one that folds up really easy in the truck, and she has a three-

**Table 3 (Cont.)**

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	<p>situations (going out and walking) while minimizing risk of falling. When others are involved in social situations, often people who are normally cane-users will choose to use a wheelchair to increase convenience for family members. Assistive devices increase opportunities for PA, but wheelchairs are seen to decrease opportunities for PA. They are to be avoided at all costs.</p>	<p>wheeler walker, which is really nice, too. It's got great big wheels, so it's easy to push. But if I can do it with a stick, I go do it with the stick. (Michael)</p> <p>They tell me it's not exercise but I've insisted on staying in a manual wheelchair because that's how I get my upper body exercise. (Maria)</p>
Disability Identity	<p>Most fear the wheelchair as the ultimate symbol of disability. Disability as part of identity includes changing expectations, embracing an MS identity (as knowledgeable, as an advocate, or involved with the MS community), experiencing and/or acknowledging ableism and inaccessibility, missing the old self, not feeling normal. Also, there is a sense of challenging current understandings of what it means to be disabled (e.g. young, invisible symptoms etc.). There are many moments of stratification of disability (I am more or less disabled than X, or at least I'm not Y)</p>	<p>Just because our bodies aren't right and are broken, doesn't mean our spirits have to be broken...But with the exercising ... I think making a team would be awesome. Just have fun. Why not? (Tammy)</p> <p>For example, to climb 2,222 steps, I'm bragging, I have bragging rights now. "Oh, I went there and I only did just 2,222 ... " "What? You did?" "Yeah, honey, I did." I did what I did and then I have MS. So, give me bragging rights. (Joyce)</p> <p>It's very thrilling to go outside. I mean, it must look like (laughs)... I'll be there with my rollator trucking right along. "Do you need help? Can I help you? Here's my cellphone who do you wanna call?" [And I'll say] "It's like rehab!" And then they're like "Oh that's great you keep going you keep at it!"... It amuses me and makes me feel good to have contact with other people. (Jessie)</p>

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## CHAPTER 6: DISCUSSION

### General Overview

The two primary purposes of this study were to 1) gain a better understanding of the myriad and contradictory ways that individuals with MS perceive exercise and physical activity as part of their self-care, and 2) to understand the ways that exercise and physical activity are used to negotiate an identity as disabled. Overall, the participants involved in this study perceive exercise to be a necessity, something they should do to stay healthy, to prevent future disability and erase current disability. They also use exercise as a form of therapy—both mental and emotional. But exercise is a double-edged sword, as it can cause stress and/or relieve stress depending on the context. For many participants, exercise is a positive and negative reminder of their old (pre-MS/pre-disability) identity, which helps them feel a sense of control over their current and future identities. At the same time, it makes apparent their fractured self-concepts and yet still helps them feel like their ‘true’ selves. These interviews highlight the instability of notions of health, fitness, disability and illness. The embodied experience of exercising with MS sheds light on important practices related to self-care behaviors among those with illness and corresponding disability. This study emphasizes the positive and negative psychological experiences with self-care discourses that aim to improve lives *and* discipline bodies.

In order to contextualize these results within the various disciplines from which I draw, I will return to the social relational model of disability. I will then discuss the implications of my research and provide an alternative paradigm for the promotion of exercise within the MS population.

### The Gap

There currently exists a gap between the fields of Disability Studies and Kinesiology. These fields have much to offer one another but they are not interacting usefully. Kinesiology’s

interaction with disability is largely rehabilitation-focused or sport/parasport-focused. Though some have begun to engage with these two fields specifically regarding exercise (see (J. J. Martin, 2013; Pack et al., 2017; Richardson et al., 2016; B. Smith & Papathomas, 2014), there exists a difficulty in conceptualizing exercise as *not* individualized or privatized—two concepts that go against the valued concepts of interdependence and social justice in disability studies. Self-care behaviors in general occupy a tenuous position within disability studies as they can be understood to return autonomy to individuals who may have experienced a loss of autonomy either as a result of their impairments or disablism, and as a means of disciplining bodies in order to conform to ablebodied norms/ideals (Clare, 2017; Kim, 2017; Reeve, 2002, 2006). I affirm that exercise works in both of these ways as evidenced by the interviews I have conducted.

In order to provide a respectful critique of medicalized exercise discourses using Disability Studies perspectives, I have chosen to utilize the Social Relational Model of Disability. This model is slightly older than the current Critical Disability Studies perspectives however, I believe it's palatability for the field of Kinesiology makes it a useful model to contextualize the results of the current study. It is not contradictory to Critical Disability Studies, rather the field has moved to more complex understandings of the relationships between the constructs of impairment effects, psycho-emotional disablism, structural disability, and identity using queer theory, crip theory, post-colonial lenses etc. Because I intend to provide an actionable critique, this model allows for those involved with the MS population in capacities related to exercise and physical activity to gain important understandings regarding Disability Studies in ways that promote change and not only critique. I will contextualize the results of this dissertation within two of the three main constructs of the social relational model of disability: Impairment effects, and psycho-emotional disablism. As previous research has highlighted the



many ways that individuals with MS experience structural disability (the third main construct of the Social Relational Model of Disability) regarding exercise participation (for example, see Schneider & Young, 2010), I will not detail that information here.

### **Impairment Effects**

Thomas defines impairments as “those variations in the structure, function and workings of bodies which, in Western culture, are medically defined as significant abnormalities or pathologies...the body itself is a social product, as well as a physically changing ‘biological’ entity...” (Thomas, 1999) p. 8. She uses the term “impairment effects” to describe:

The direct and unavoidable impacts that ‘impairments’ (physical, sensory, intellectual, emotional) have on individuals’ embodied functioning in the social world. Impairments and impairment effects are always bio-social and culturally constructed in character, and may occur at any stage in the life course. (Thomas, 2012) p 211

Exercise *can* reduce symptoms and impairments among those with MS (Ensari, Motl, & Pilutti, 2014; Latimer-Cheung, Martin Ginis, et al., 2013; Latimer-Cheung, Pilutti, et al., 2013; Motl & Pilutti, 2012; Motl & Sandroff, 2015), and anecdotally does among the participants in this study. Conversely, impairments *can* and *do* reduce exercise participation and impact the ways that individuals with MS engage in exercise. This population engages in less physical activity than the general population but roughly the same amount as other ‘clinical’ populations (Kinnett-Hopkins et al., 2017) and as discussed in chapter 3, relapses are moments where MS impairment drastically reduces physical activity participation (or in many cases completely stops it) (Adamson, Adamson, Littlefield, & Motl, 2017).

Several subthemes highlighted the role of exercise in coping with and understanding impairments and impairment effects. First of all, throughout all themes participants described the impact of impairments on their actual exercise behavior. Their symptoms such as fatigue, mobility impairment, numbness and weakness made many exercises that they formerly

participated in either more challenging or impossible. The ways that MS makes exercising more difficult has been extensively studied previously (Learmonth & Motl, 2016; Motl, Snook, & Hinkle, 2007; Snook & Motl, 2008), however, the results of the current study highlight that the differential between past and current abilities as particularly challenging for individuals with MS. The impairments of fatigue, loss of mobility and weakness when combined with cultural imperatives of maintaining youthfulness, strength and fitness (Markula & Pringle, 2006) result in sadness and feelings of loss over the impairments leading to non-participation. This melding of biological reality with social ideals and norms, especially when occurring in this population of younger adults who ‘shouldn’t’ be experiencing deterioration of this magnitude so young, seems to contribute to the imperative to engage in exercise for the purpose of reducing unwelcome impairments. Research among adults with varied neurological conditions echo the difficulty in experiencing impairments at younger ages when disease and disability are socioculturally associated with older age (Hutchinson, Roberts, & Daly, 2018).

The imperative to engage in exercise in order to reduce impairment was described in the themes ‘Constant Vigilance: I *should* exercise’ and ‘Actively Avoiding Inactivity.’ Because participants felt that they could reduce impairments and impairment effects with exercise (and as a result of the general Western emphasis upon fitness (McKenzie, 2013)), they were often thinking about exercise and felt a great deal of stress as a result. When exercise was discussed in disciplinary or health-promoting terms, this was especially true. However, when they discussed the mentally and emotionally therapeutic benefits of exercise, they did not discuss the importance of vigilance over their exercise behavior similarly.

## Psycho-emotional disablism

Psycho-emotional disablism involves the ‘socially engendered undermining of [impaired peoples’] psycho-emotional well-being’(Thomas, 1999, p. 60) and is an equally important contributor to the experience of disabled individuals as structural disability and limitations to participation in society. Perhaps the most important theme to provide examples of psycho-emotional disablism in the context of MS and exercise is the theme ‘Schisms in Self.’ In this theme, participants described themselves in a variety of dualisms, i.e. that I am not my body, there is an old self and a new self, and the MS self is not their true self. They in essence *other* the parts of themselves that do not align with social ideals of normalcy. This does not happen simply because there are parts of themselves that they do not accept, but because those parts of themselves are sometimes temporary, fleeting, ambiguous, and fluctuate. Their self-concepts are fractured because their experience mirrors this fracture. Therefore, the psychological loss they experience is tied up with the in-betweenness of their impaired state *in addition to* messages of compulsory ablebodied/ablemindedness.

Previous research confirms the fractured and liminal self-concepts described by the participants of this study (Barker et al., 2014; Grytten & Måseide, 2005; Lexell et al., 2009; Mozo Dutton et al., 2012; Skår, Folkestad, Smedal, & Grytten, 2014). Mozo-Dutton et al highlight the ways that a person’s relationship to their body changes with MS and bodies come to be seen as unreliable, or untrustworthy. Vick however highlights the role of larger political and discursive forces contributing to the experienced liminality. She states “The politics of inhabiting a body that is anti-identarian (McRuer, 2006)—that occupies a ‘grey area’ because it is physically capable one day, requires accommodation another, and is incapable the next—exceeds set taxonomies and becomes an unimaginable problem.” (Vick, 2013). This

unimaginable problem is visible in the ways that persons with MS struggle to obtain disability benefits (Lightman, Vick, Herd, & Mitchell, 2009) because they do not appear disabled ‘enough.’

Research by Grytten and Maseide indicates that individuals with MS experience stigma in the form of the perceived illegitimacy of MS as a disability warranting welfare benefits or other forms of assistance (Grytten & Måseide, 2005). The challenge to inhabit the liminal, ambiguously disabled body may also be reflected in the apparent ambiguity of control over MS with exercise that was discussed by the participants in this study. Participants used exercise as a way to exert control over the ambiguity of their embodiment. When their symptoms were mild, they exercised to prevent future disability or to prepare themselves (to be fit) for future relapses. When their symptoms and impairments were more moderate, they exercised to regain mobility in addition to preventing worsening impairment. When their symptoms and impairments were severe (such as in the case of full-time wheelchair users) some exercised for more habitual reasons, not necessarily to reverse disability. This indicates that the ambiguity of the ‘threat’ of future impairment is what may be driving the urge to exercise to prevent impairment. Their uncertainty regarding future impairment results in a tendency towards constant vigilance over their exercise behavior and their sedentary behavior. Too little exercise and too much sedentary behavior are unambiguously associated with future disability for those who are more newly diagnosed or have mild-moderate impairment. Those who have had MS for much longer do not have the same tendency towards constant vigilance even if their impairment is mild. They seemed to have crossed into the post-liminal identity (Strickland et al., 2017) and are not as uncertain about their futures with MS.

**Loss.** Kafer discusses the concept of ‘compulsory nostalgia’ as especially relevant for individuals with ‘acquired’ impairments (such as MS) who often describe themselves as multiple selves (before and after disability). Compulsory nostalgia is the expectation that individuals with acquired impairments will long for the ‘old self’ and given the opportunity for a cure would always take the cure to rid themselves of their current self. Indeed, our participants echoed a desire for cure but in the absence of cure would engage in self-care behaviors and MS management to minimize the loss they could experience in the future. “The ‘after’ self longs for the time ‘before’” as Kafer says, but the “after” self, as described by the participants in this study, also fears future selves, future selves with even more loss, even more disability. Kim describes this as “freezing time to prevent the future of further disability” (Kim, 2017, p. 231) which works differently than “folding time,” the trend to eliminate the present by longing for the nondisabled past or the cured future (something that these interviews also demonstrated). The vehicles for freezing and folding time are not only cure in the absolute sense. She discusses the ways that many activities become understood as rehabilitative (medicalized) when disabled people do them, beginning with a quote from Tari Youngjun Na:

“We shivered whenever we heard the word ‘therapy.’ When disabled people did music, it became music therapy; exercise became rehabilitation therapy; stage acting became theater therapy; painting was quickly named as art therapy. Even though these activities could be used for the purpose of treatment, we knew that, regardless of specific purpose or content of an activity, they were so easily considered therapies, because of the belief that disability should be cured.” Kim continues: The need for cure extends to the activities of life and transforms them into exceptional interventions solely for the purpose of ‘improvement,’ with the eventual aim of eliminating disability or of approximating able-bodiedness. (Kim, 2017, p. 5)

Exercise was described by this group of participants as physically rehabilitative and as mentally/emotionally *therapeutic*. Exercising outside had an especially therapeutic effect. Kafer

describes her own feelings about outdoor activities and her sense of loss regarding the ways she now participates in them:

I cannot deny that I feel different ‘outside,’ away from traffic and exhaust pipes and crowds of people. That I have been conditioned to feel this way does not change the fact that I feel more at peace in my body when perched on the side of a cliff, or gazing over a meadow, or surrounded by sequoias. (Kafer, p 140)

She acknowledges the ways that nature has been constructed to be peaceful, but many of the participants in this study used the word ‘therapeutic’ relating to Na’s assertion that regardless of the purpose of an activity, it can be considered therapeutic because of the need to reduce disability. For this group of individuals with MS, exercise was therapeutic physically and emotionally-potentially holding in tension internalized oppression (i.e. compulsory ablebodiedness or approximating ablebodiedness) and using exercise as a coping mechanism for dealing with disablism and impairment effects.

The sense of loss that many individuals described regarding their abilities to exercise was not only in relation to their inability to complete certain functions any longer. They felt a sense of loss regarding their previous self-concepts as “a gym rat” or an “athlete” and the impairments that limited them from engaging in those activities were difficult to manage otherwise. Eli Clare acknowledges the difficulty of the in-between position of loss and acceptance. He says “I think about how we might bear witness to body-mind loss while also loving ourselves just as we are right now. I begin to understand restoration... as one particular relationship between the past, present, and future.” (Clare, 2017, p. 60). Exercise could hold this place, a reminder of the things one used to love to do, a recognition of a new embodiment, and a way to creatively navigate that new embodiment in ways that fulfill similar purposes of contributing to a self-concept, having mental and emotional peace, and restoring aspects of the former embodiment.

**Disbelief.** As I described in the Results section, several participants (but not the majority) discussed the disbelief they encountered from family members regarding their MS symptoms and experience in general and also in relation to exercise. For some, family members and friends did not believe the participants were limited as much as they said they were and these family members and friends tried to encourage more exercise participation. Some also felt that when family members/friends saw them exercising it negated the credibility regarding their MS experiences (e.g. if you can walk that far, your MS must not be as bad as you say it is.) Therefore, the role of invisibility as a hallmark characteristic of MS is at play and influences decisions regarding exercise. Vick also describes the role that exercise plays in disbelieving attitudes from family members when occasional bursts of energy resulting in exercise participation are taken as evidence of the non-severity of MS (Vick, 2013).

### **Moving from Discipline to Resource**

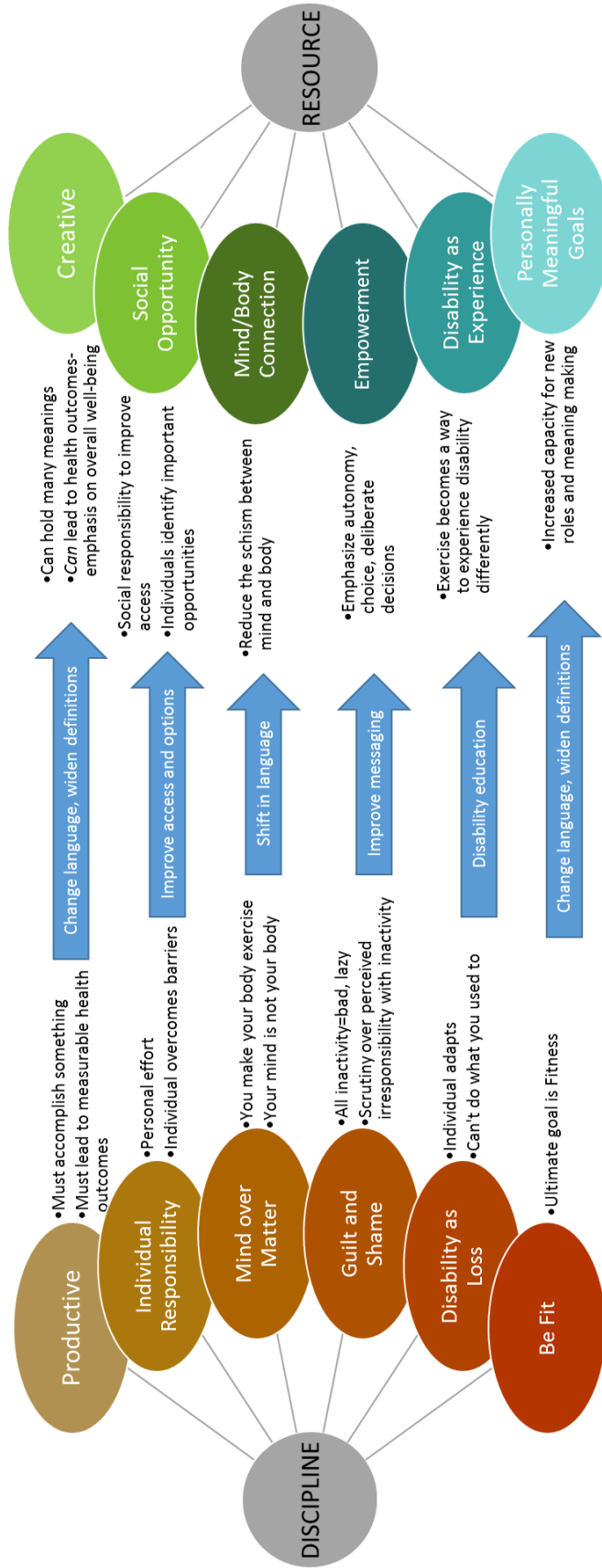
For all the physical benefits it provides, exercise should not be viewed as an unassailable good. A certain measure of physical activity is necessary for one's well-being, but the value judgements, associations, and moralisms that have become a part of fitness culture complicate the practice of exercise. (McKenzie, 2013, p. 8)

Exercise as medicine emphasizes a disciplinary approach to bodily movement. The interviews in this study provide examples of the ways that individuals with MS use exercise to: manage symptoms, prevent or reverse disability, engage in the social world, and to be productive. However, individuals also use exercise because: it is enjoyable, it is mentally and emotionally beneficial, it helps them feel connected (mind/body), and it helps them do the things that are important to them in the face of structural disability. They simultaneously accept certain discourses about disability (that it is to be avoided and is undesirable) while challenging others (that they are helpless, have no control, and are sick). Exercise as discipline has several

undesirable side effects, including guilt, shame and increased stress. Indeed, in the MS population, several adverse psychological consequences have been reported as consequences of exercise participation including frustration, loss of control, depression, anxiety, and feelings of inadequacy as well as facing structural barriers to exercise devaluing their participation as disabled individuals (Learmonth & Motl, 2015). In order to maximize the positive benefits of exercise while avoiding the negative outcomes of a medicalized, disciplinary exercise, I propose a paradigm shift: from exercise as discipline to exercise as resource. See figure 1 to compare components of the old and new paradigm.



Figure 1. Paradigm Shift from Exercise as Discipline to Exercise as Resource



To move forward towards a more responsible ethic of exercise promotion, it is important to consider the question posed by Nieri and Hughes (though their focus was on gendered fitness, not ableism and disability): "the larger issue at hand is the extent to which participation in an [ableist] activity-- in this case, fitness-- reproduces structural [disability and health] inequalities, even if the activity involves individual-level outcomes (e.g. [strong people with disabilities]) that contradict the ideology supporting the disability structure (e.g. [people with disabilities are weak])." (Nieri & Hughes, 2016). In other words, is there a way to conceptualize exercise as a way to reduce negative experiences with MS symptoms (impairments) without contributing to ableism and compulsory ablebodied discourse? Can exercise be promoted in ways that contribute to healing of the body and healing of the mind/body schism? Can exercise help people with MS to navigate an identity as descriptively *and* politically disabled? An ethically responsible exercise promotion practice in this population would need to contradict the disability structure (that disability is individual and medical and it should be overcome through individual effort) while also contributing to individual-level outcomes (e.g. improved symptoms and a positive sense of disability identity). Returning to Siebers' goal of his theory of disability identity: to "give disabled people greater knowledge of and control over their bodies in situations where increased knowledge and control are possible." (Siebers, 2008, pp. 14-15), conceptualizing and interacting with exercise as a resource should involve giving individuals with MS greater knowledge of and control over the parts of their embodied experience where greater knowledge and control are possible, but no further; acknowledging the limits of exercise's capacity to alter their impairments and relocating responsibility for this outside of the individual.

Markula has written extensively regarding Foucault's concept of the technologies of the self and the ways that women in particular are empowered to counter technologies of power

through sport and exercise (Markula, 2003, 2004; Markula & Chikinda, 2016; Markula & Pringle, 2006). In discussing the ways that sport might transgress the discursive practices that hold exercise and sport as discipline, she affirms that the ethical care of the self engages with the opportunity to be ‘other’ and actively negotiates an identity as such:

“Lloyd reads Foucault’s conceptualization of emancipation as an individual’s ‘freedom to invent a self’ (Lloyd, 1996, p. 25): through self-awareness individuals create new types of experiences that can lead to transgressive practices. These practices further establish a chance for public impact by provoking confusion about the present discourse...”

The participants in this study at times transgressed expectations about what an MS body could do in terms of exercise. For some, this came at a cost, i.e. disbelief regarding their MS impairments, and for many this was manifest in their self/MS dualism. They exerted control over MS through exercise, when they understood MS as out of their control. Aujoulat et al describe the double process of ‘holding on’ and ‘letting go’ as empowering ways to integrate conflicting aspects of a self-concept. By ‘holding on’ to a self-concept separate from illness and ‘letting go’ of control over the uncontrollable aspects of illness, individuals with chronic illness can reconcile their sense of self and be empowered to experience illness/disability rather than manage disease (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008). Exercise already seems to be associated with holding onto a self-concept separate from MS but does not seem to contribute to ‘letting go.’ Therefore, persons with MS may use exercise to empower themselves only within a structure that encourages a return to ablebodiedness at whatever personal cost. Shapiro, Schwartz and Astin state “when events are beyond an individual’s personal control, problems may be exacerbated by persistent efforts at control, a strong sense of self-efficacy, or a high desire for control.” (Shapiro Jr, Astin, & Schwartz, 1996, p. 1216). Therefore, maintaining the paradigm of exercise as discipline and continuing to emphasize personal responsibility to maintain

able-bodiedness for as long as possible close off both individual possibilities for empowerment through “letting go” and social possibilities of change through transgressive practices.

Following Hahn’s shift of viewing ‘disability as an experience rather than a loss,’ (Hahn, 1997, p. 34), Hutchinson et al. identify empowerment as an important component of identity renegotiation among those with acquired neurological conditions (Hutchinson et al., 2018). Because exercise is already perceived as (sometimes) empowering for those with MS (Adamson et al., 2017), and, as the results of the current study demonstrate, is already tied up in the process of disability identity negotiation, removing the negative components of exercise messaging and experience (those which lead to guilt, shame, and fracturing of the self-concept) may empower individuals with MS to navigate a liminal identity as descriptively disabled and to adopt an identity as politically disabled all while managing MS impairment with exercise. Susan Wendell addresses the tenuous place of individuals such as these in disability activism and disability studies. She says:

...some people with disabilities *are* sick, diseased, and ill. Social constructionist analyses of disability, in which oppressive institutions and policies, prejudiced attitudes, discrimination, cultural misrepresentation, and other social injustices are seen as the primary causes of disability, can reduce attention to those disabled people whose bodies are highly medicalized because of their suffering, their deteriorating health, or the threat of death. Moreover, some unhealthy disabled people, as well as some healthy people with disabilities, experience physical or psychological burdens that no amount of social justice can eliminate. Therefore, some very much want to have their bodies cured, not as a substitute for curing ableism, but in addition to it. (Wendell, 2001, p. 18)

How might exercise act as an agent of change for curing ableism while alleviating impairments among those with MS? What needs to happen to exercise promotion practices to hold these two goals in tension? What can the experience of exercising with MS elucidate for other disabled populations and for Disability Studies?

## **Strengths and Limitations of the Study**

There are several strengths to the current study. First, this study is one of few qualitative studies to include individuals with MS with severe impairment. Adding their perspectives provided valuable contrast to those with mild and moderate impairment. Because increased severity of impairment is associated with disability identification (Bogart et al., 2017), these perspectives are essential to understanding the role of exercise in the negotiation of an identity as disabled. My research suggests that indeed those with severe impairment are more likely to use exercise in ways other than to prevent disability whereas those with mild-moderate impairment are much more likely to use exercise in this way. There are exceptions however, those with severe impairment but who are not full-time wheelchair users actively work to avoid becoming ‘dependent’ upon a wheelchair and use exercise as a means to do so.

This study highlights the possibilities of engagement between the fields of Disability Studies and Kinesiology where the goals of each might be met through the other. Exercise participation might be used as a vehicle to mobilize a large proportion of descriptively disabled individuals into politically disabled identity; a diverse group of individuals who can contribute to understandings of disability, and work towards disability justice. Likewise, understandings of the experiences of disabled individuals from a Disability Studies perspective can help the field of Kinesiology to promote exercise in more ethically responsible ways, contributing to their goals of improving health and quality of life through movement.

This study has several limitations worth discussing. First of all, the interviews chosen for this study did not represent a homogenous sample of individuals with MS as is encouraged by the IPA methodology. The participants varied greatly based on race, age, time with MS, severity of MS impairment, sexuality, and weekly exercise participation level. Due to the intensive nature

of IPA analysis, I spent most time with individual interviews instead of grouping individuals based on these varied characteristics. In the future, I aim to return to these interviews and give a more careful consideration of the ways that these factors influence the roles that exercise fulfills for these individuals as well as their relationships with a disability identity.

Secondly, participants' abilities to express their experiences and interpretations of those experiences is central to IPA as a method. These are difficult concepts and many if not most of the participants involved are naïve to social understandings of disability and have only been exposed to medical understandings of disability. Therefore, my interpretations of their relationship to exercise and disability has been filtered through their expressions in terms contrary to the ones I am using to contextualize the results. I believe I have given a defensible reading of the stories that were shared with me though I recognize the sharing in and of itself does not indicate their lived reality with great precision.

Lastly, I regret that I was unable to contribute to a more detailed analysis of the intersecting identities of the participants of this study. The participants represented a diversity of sociocultural backgrounds and in the future, I aim to give priority to these explorations.

## CHAPTER 7: CONCLUSIONS

This dissertation has been an exploration into the roles that individuals with MS perceive exercise to hold in relation to their self-care and identity as disabled. I have used the Social Relational Model of Disability to contextualize the MS experience and to frame the results of this study. Overall, exercise fulfills many roles for the individuals with MS that I interviewed. These include: to manage MS, to enhance self-worth, to feel productive, to engage socially, to prepare for big events, to relax, to improve mental well-being, to prevent future disability, to reverse current disability, and to stay healthy. They fulfill these roles through being constantly vigilant about their exercise behavior, actively avoiding sedentary behavior, and by making conscientious decisions about when and where to use assistive devices in order to maximize physical activity and minimize dependence upon assistive devices. The effects of these orientations to exercise on their sense of self are varied. They experience fractured self-concepts across a variety of continuums including mind/body, old self/new self, MS self/true self, and healthy/unhealthy. The relationship between exercise and disability identity involves pushing away from disability by exercising for those with ambiguous descriptive disability and for some with clear descriptive disability. Others with more severe disability or who have had MS for many years are beginning to indicate movement towards political disability identity. Exercise and physical activity do not take on the roles of removing disability for these individuals, rather they are activities where people recognize ableism, and structural disablism in the form of inaccessibility. They also use exercise to adapt and prepare for situations inhospitable to disabled individuals. Overall, as currently promoted, the main role of exercise as it relates to disability identity is to prevent or remove descriptive disability.

I have proposed an alternative exercise promotion paradigm where emphasis upon exercise as discipline moves towards viewing and promoting exercise as a resource. Some may wish to use exercise as a resource to navigate and alleviate aspects of their disability and impairment, while others who are working towards affirming their descriptive disability could participate in exercise for reasons other than to change their embodiment. Moving away from exercise as productive to exercise as creative allows for wider variation in what exercise might look like, what ‘counts’ as exercise and what individuals with MS might feel empowered to engage in (outside of walking, going to the gym or physical therapy). By shifting the focus from individual responsibility to creating opportunities and improving access to exercise for this population, this structural barrier to participation can be addressed. Because individuals with chronic illness are already likely to experience a fractured self-concept, exercise promotion language can begin to emphasize mind/body connection with exercise; that exercise is not about a self who is motivated to exercise trying to motivate an unmotivated body. The frequently mentioned outcomes of guilt and shame from disciplinary health promotion messages can be replaced with empowerment through increased autonomy over exercise decisions. With increased accessible opportunities and greater latitude to make many meanings regarding exercise, I expect individuals to experience greater autonomy over the decisions of when/how/if to exercise. Medical framing of disability as a loss of capacity and self-hood can be altered to conceptualize disability as experience, and exercise is one of many ways to experience a new embodiment. Lastly, by removing the ultimate goal of disciplinary exercise, i.e. fitness, participants can use exercise as a resource for fulfilling many goals in various aspects of their lives.

To end, I return to Erevelles:



What is my relationship to disability? With what authority can I speak about disability? And why? Am I speaking with disabled people or about them?... Disability studies' eternally changeable borderlands make these questions relevant to everyone, whether they identify as disabled or not at any given time. And just in case someone argues to the contrary, belonging and identity are not idle insertions into political discourse; rather they have critical implications for how the field of disability studies continues to expand and thrive within a future that is, as yet, tentatively unimaginable and tantalizingly possible. (Erevelles, 2014)

Belonging and identity have critical implications for the future of the field of Disability Studies.

What if those on the borderlands, those with liminal disability, episodic disability and invisible disabilities were empowered to identify and belong here? In what ways would the field expand?

In what ways would structural and psycho-emotional disablism change with a mobilized community of in-betweeners?

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## APPENDIX A: INTERVIEW GUIDES FROM ANALYZED STUDIES

### PEMS Interview Guide:

#### *Photoelicitation questions:*

What is the image?

What is happening in the image?

Why this image is important to you?

Does the picture relate to your personal decision to be active or inactive? Why?

Is that a barrier or a facilitator for being active?

#### *Remainder of Interview:*

##### A. Individual level

Broader question: What does living healthy mean to you?

- What does physical activity mean to you? Is physical activity the same as exercise?
- How important is physical activity to you? To your health? What is physical activity's role in your life, and your health?
- How much physical activity do you think you should do? What kind of physical activity/exercise is good for people with MS?

##### B. Relationship level (family; social network, etc.)

Broader question: Tell me about your role in your family?

- Do you receive support from your family and friends to be physically active? Can you tell me about that support? Why is it helpful or unhelpful?
- Do you receive support from organizations such as NMSS to be more active? Can you tell me about that support? Why is it helpful or unhelpful?
- What kinds of physical activity do your family members engage in?

- In what ways do you think your family, friends encourage or discourage you to be more active?

### C. Community level

Broader question: How do you feel about your neighborhood?

- Tell me about your neighborhood.
- Is it easy to be physically active in your neighborhood? What makes it easy? What makes it hard?
- Are there any groups or programs in your neighborhood that promote health and physical activity? Can you tell me about them? How would you improve them?
- Are you aware of recommendations of physical activity for persons with MS?
- Did your primary doctor or neurologist ever recommend exercise/PA for you? How do you perceive these recommendations?
- Where do you get most of your information regarding PA?
- What do you see as the impact of PA/Exercise in your life? In other words, what is PA/Exercise helping you to do or be? [Probe about areas of their life...keeping working, social participation, mentally, etc.]
- How do you see yourself without doing physical activity?

## **RELAPSE Interview Guide:**

Individual perspectives regarding physical activity

What does physical activity mean to you?

How does physical activity differ from exercise?

Tell us about your usual physical activity routine.

What forms of physical activity do you participate in/enjoy?

How do you see physical activity fitting into your life? Your treatment of MS symptoms?

Experiences surrounding physical activity related to relapse

Tell us about your physical activity routine before your last relapse.

What did you participate in? What was normal for you?

Tell us about your physical activity during your last relapse.

Did it increase or decrease? Why?

What aspects of your relapse made it difficult to return to or maintain your normal routine?

What did your neurologist (or other healthcare professional) tell you during your relapse about physical activity?

Concerns regarding return to physical activity following a relapse

What about your relapse concerned you regarding your ability to exercise?

What aspects affected your return to normal activity? What questions arose?

What additional concerns regarding physical activity arose after your relapse?

Did you bring these up with your neurologist? Or other healthcare professional. What did he/she say?

How else did you resolve your concerns/questions? Who/what else did you turn to?

Experience with managing the uncertainty of relapse and re-establishing certainty

How did your relapse affect your confidence in your ability to exercise as you normally do?

What changes occurred as a result of your relapse? How did you adapt to those?