A NEEDS ASSESSMENT TO INFORM THE DEVELOPMENT OF A
DYADIC PHYSICAL ACTIVITY INTERVENTION FOR CAREGIVER
CARE-RECIPIENT DYADS WITH MODERATE-TO-SEVERE MULTIPLE
SCLEROSIS DISABILITY

by

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A thesis submitted to the School of Rehabilitation Therapy
In conformity with the requirements for
the degree of Doctor of Philosophy

Queen’s University
Kingston, Ontario, Canada
(November, 2017)

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Abstract

The impact of multiple sclerosis (MS) extends beyond the person who has the disease to his/her family caregivers. One of the rehabilitation strategies to manage some of the disease impact on the health of both partners is increasing participation in physical activity. Yet, physical activity interventions in MS rarely focus on people with moderate-to-severe MS disability or target dyads.

The overall purpose of this dissertation was to determine if there is sufficient evidence to support the development of a dyadic physical activity intervention for people with moderate-to-severe MS disability and their family caregivers. Guided by the Developmental Contextual Coping Model and the Concerns Report Methodology, three studies were conducted as part of this dissertation. First, a qualitative focus group study was conducted to explore the shared perspectives of the dyads about physical activity. Next, a cross-sectional accelerometry study was conducted to determine physical activity pattern interdependence within the dyads. Finally, a cross-sectional survey study was conducted to determine the needs, issues and concerns for community resources to support physical activity participation, factors associated with perceived need and barriers to sole- versus co-participation in physical activity among the target groups.

The results indicate that structured and unstructured physical activity are not perceived as mutually exclusive and each partner can go back and forth along the continuum depending on current circumstances. Physical activity was described an interpersonal experience with caregivers and care-recipients sharing similar struggles, frustrations and adjustments when trying to be physically active. The results also show that both people with moderate-to-severe MS disability and their caregivers are far below the public health recommendations for physical activity. Findings highlight the critical need for a multilevel resource that incorporates affordable options for exercising together and innovative methods of outreach to people with moderate-to-severe MS disability and the caregivers who support them. A broad range of predisposing, enabling and health need factors were associated with perceived need for community resources. The variability in barriers to sole- versus co-participation in physical activity
among people with MS and their caregivers suggest that the success of dyadic physical activity interventions in MS may be contingent upon adequate diminution of care-recipients and caregivers unique barriers.
Co-Authorship

The manuscripts presented in this dissertation are the work of Afolasade Fakolade in collaboration with her co-authors. For all manuscripts, Ms. Fakolade was responsible for developing the research questions and the study design; developing research tools including interview guides and questionnaires; entering, and analyzing data; and writing the manuscripts. The co-authors of the manuscripts are Dr. Marcia Finlayson (manuscripts 1 through 3), Dr. Amy Latimer-Cheung (manuscripts 1 through 3), Dr. Trisha Parsons (manuscripts 1 through 3), Dr. Sarah A. Morrow (manuscript 1), and Ms. Julie Lamarre (manuscript 1).

**Manuscript 1:** Understanding leisure-time physical activity: Voices of people with MS who have moderate-to-severe disability and their family caregivers. This manuscript is published in *Health Expectations*. Dr. Finlayson provided input regarding the research question, development of the focus group interview guide, training to conduct the focus groups, guidance in study design, data analyses, interpretation of results, and editorial feedback on the manuscript. Dr. Latimer-Cheung provided input regarding the research question, guidance in study design and interpretation of results, and editorial feedback on the manuscript. Dr. Parsons provided input regarding the research question, supervision during the focus group meetings, guidance in study design, analysis and interpretation of results, and editorial feedback on the manuscript. Dr. Morrow offered recommendations for recruitment, provided supervision during the focus group meetings and editorial feedback on the manuscript. Ms. Lamarre provided input during data analysis, interpretation of results and writing of the manuscript.

**Manuscript 2:** Correlating physical activity patterns of people with moderate-to-severe multiple sclerosis disability and their caregivers. This manuscript is in press in *Physiotherapy Canada*. Dr. Finlayson provided input regarding development of the research question, study design, data analysis, interpretation of results and editorial feedback on the manuscript. Dr. Latimer-Cheung provided input regarding the
research question, study design, data analysis, interpretation of results, and editorial feedback on the manuscript. Dr. Parsons provided input regarding the research question, study design, data analysis, interpretation of results, and editorial feedback on the manuscript.

**Manuscript 3**: A concerns report survey of physical activity support needs of people with moderate-to-severe MS disability and their caregivers. This manuscript is currently under review in *Disability and Rehabilitation*. Dr. Finlayson provided input regarding the research question, development of survey instruments, study design, data analysis, and interpretation of results, as well as editorial feedback on the manuscript. Dr. Latimer-Cheung provided input regarding the research question, development of survey instruments, study design, data analysis, and interpretation of results, as well as editorial feedback on the manuscript. Dr. Parsons provided input regarding the research question, development of survey instruments, study design, data analysis, and interpretation of results, as well as editorial feedback on the manuscript.
Acknowledgements

First, I wish to thank my supervisor Dr. Marcia Finlayson for her support and guidance throughout this journey. Over the last four years, you have challenged me to push the boundaries of what I currently know, and to think critically about how we conduct MS rehabilitation research now and how we need to proceed in the future. You have provided me with a solid foundation and the confidence to succeed as an independent researcher. I am grateful for the opportunity to have been mentored by you.

I would like to thank members of my dissertation committee: Dr. Amy Latimer-Cheung and Dr. Trisha Parsons. From our first meeting for my comprehensive exams to date, it has been an absolute delight to work with you. The critical and thoughtful feedback you provided on every aspect of my research and writing have strengthened my work and improved my skills as a researcher.

I would like to thank Dr. Sarah Morrow and Ms. Denise Bowman for their tremendous help with recruiting participants for this dissertation work.

I would also like to acknowledge all the people with MS and their family caregivers who participated in the three studies conducted as part of this dissertation work. This thesis would not have been possible without you.

Thanks to the following agencies who provided me with generous funding for my research: The Multiple Sclerosis Society of Canada Doctoral Studentship, The Canadian Disability Participation Project and The Ontario Graduate Scholarship.

To all my friends and colleagues in the MS Rehabilitation Research Team and OCA, for the company and laughs throughout my time at Queen’s.

To my mom and siblings, thank you so much for your continuous support and prayers. Words cannot express how truly grateful I am to have you all in my life.
To my husband, **Tola**, thank you for your patience and support during what I am sure, at times seemed to you, like my never-ending student life. Thank you for spending numerous nights in the library keeping me company as I wrote this thesis. Thank you for believing in me, praying with me, and keeping me motivated and on track in times when I could not see the light at the end of the tunnel.

To my little **Stefan**, you have brought so much joy to my life and the journey has certainly been more fun since you arrived.

This work is dedicated to my **dad**, who passed away a few months before I completed the PhD. You invested so much of your life in me and I will never forget you.
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<th>Full Form</th>
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<tbody>
<tr>
<td>ADLs</td>
<td>Activities of daily living</td>
</tr>
<tr>
<td>APIM</td>
<td>Actor Partner Interdependence Model</td>
</tr>
<tr>
<td>BBB</td>
<td>Blood-brain barrier</td>
</tr>
<tr>
<td>CG</td>
<td>Caregiver</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence intervals</td>
</tr>
<tr>
<td>CMSCCI</td>
<td>Coping with Multiple Sclerosis Caregiving Inventory</td>
</tr>
<tr>
<td>CNS</td>
<td>Central nervous system</td>
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<tr>
<td>DS</td>
<td>Disease Steps</td>
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<tr>
<td>EDSS</td>
<td>Expanded Disease Severity Scale</td>
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<tr>
<td>ES</td>
<td>Effect sizes</td>
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<tr>
<td>FS</td>
<td>Functional systems</td>
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<tr>
<td>HAPA</td>
<td>Health action process approach</td>
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<tr>
<td>IQR</td>
<td>Interquartile range</td>
</tr>
<tr>
<td>LPA</td>
<td>Light physical activity</td>
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<tr>
<td>MHC</td>
<td>Major histocompatibility complex</td>
</tr>
<tr>
<td>MRC</td>
<td>Medical Research Council</td>
</tr>
<tr>
<td>MRI</td>
<td>Magnetic resonance imaging</td>
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<tr>
<td>MS</td>
<td>Multiple sclerosis</td>
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<tr>
<td>MSWS</td>
<td>Multiple Sclerosis Walking Scale-12</td>
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<tr>
<td>MVPA</td>
<td>Moderate to vigorous physical activity</td>
</tr>
<tr>
<td>NARCOMS</td>
<td>North American Research Committee on Multiple Sclerosis</td>
</tr>
<tr>
<td>NG</td>
<td>Need gap</td>
</tr>
<tr>
<td>NI</td>
<td>Need index</td>
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<tr>
<td>OR</td>
<td>Odds ratio</td>
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<tr>
<td>OT</td>
<td>Occupational therapists</td>
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<tr>
<td>PALMS</td>
<td>Personal Activity Location Measurement System</td>
</tr>
<tr>
<td>PDDS</td>
<td>Patient Determined Disease Step</td>
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<tr>
<td>PI</td>
<td>Principal investigator</td>
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<tr>
<td>PPMS</td>
<td>Primary progressive multiple sclerosis</td>
</tr>
<tr>
<td>PRMS</td>
<td>Progressive relapsing multiple sclerosis</td>
</tr>
<tr>
<td>PT</td>
<td>Physiotherapists</td>
</tr>
<tr>
<td>QOL</td>
<td>Quality of life</td>
</tr>
<tr>
<td>RA</td>
<td>Research assistant</td>
</tr>
<tr>
<td>RRMS</td>
<td>Relapsing remitting multiple sclerosis</td>
</tr>
<tr>
<td>SD</td>
<td>Standard deviation</td>
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<tr>
<td>SDT</td>
<td>Self-determination theory</td>
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<tr>
<td>SPMS</td>
<td>Secondary progressive multiple sclerosis</td>
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<tr>
<td>ST</td>
<td>Sedentary time</td>
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</table>
Chapter 1 Introduction

1.1 General Introduction

Multiple sclerosis (MS) is an inflammatory disease of the central nervous system (CNS) that ultimately leads to neuroaxonal destruction in various structures including the spinal cord, brainstem, cerebellum, cerebrum and optic nerves\(^1,2\). The progressive nature of MS and associated disability means that many people with this disease, especially those individuals with higher levels of disability, often need on-going support from family caregivers as the disease progresses\(^3,4\). Providing such on-going support contributes to MS caregiver burden due to the physical and emotional dependency that develops with greater disease severity among the care-recipients\(^5\). Caregiver burden can adversely impact the person with MS, affecting both the quality of care provided and the partnership between the caregiver and the care-recipient\(^6,7\). Together this evidence suggests that the impact of MS extends beyond people with the disease to the family caregivers who support them\(^8,9\) and highlights the importance of considering the health of the person with MS and family caregiver as an interdependent unit rather than each in isolation.

One of the rehabilitation strategies to manage some of the disease impact on both people with MS and their caregivers is increasing participation in physical activity. Thus, physical activity has become an important component of comprehensive MS care and is the major topic of this dissertation.

1.2 Dissertation Overview

The research is presented as three manuscripts, each contributing to the overall purpose: *to determine if there is sufficient evidence to support the development of a dyadic physical activity intervention for people with moderate-to-severe MS disability and their family caregivers.* The specific aims are to:

1) Describe the shared perspectives of people with moderate-to-severe MS disability and their family caregivers about physical activity (manuscript 1);
2) Determine physical activity pattern interdependence within dyads affected by moderate-to-severe MS disability (manuscript 2); and

3) Identify the needs, issues and concerns of the target groups regarding community resources to support physical activity participation (manuscript 3).

In addition to these three manuscripts, this dissertation includes this introduction, a literature review, and a consolidation chapter. Each of these components is summarized below.

Chapter two reviews the available literature pertaining to MS and physical activity. It highlights the gaps and limitations in the current MS literature, and provides the rationale for this dissertation. Finally, the theoretical framework and overarching methodology guiding the dissertation are discussed.

Chapters three through five present the three manuscripts; each manuscript addresses one research aim. The first manuscript describes the shared perspectives of people with moderate-to-severe MS disability and their family caregivers about physical activity. A qualitative focus group method was used. Twenty-three people with MS and 12 family caregivers participated in the study. This study provides three important insights. First, physical activity is an interpersonal experience with people with MS and their family caregivers sharing very similar struggles, frustrations and adjustments when trying to be physically active. Second, the need to adopt an integrative approach that acknowledges the caregiver-care-recipient dyad as a focus for physical activity intervention is highlighted. Third, researchers designing interventions need to move beyond focusing solely on promoting structured exercise but also encourage everyday activity as a means of improving physical activity levels among people with moderate-to-severe MS and their caregivers.

The second manuscript describes the assessment of dyadic physical activity using accelerometers. This study is novel because it includes simultaneous assessment of physical activity among matched caregiver
care-recipient MS dyads. Fourteen dyads participated in this exploratory, descriptive observational study. Although the findings do not support the notion of physical activity pattern interdependence within the dyads, they do show that as with many Canadian adults, people with moderate-to-severe MS disability and their caregivers are not engaging in sufficient physical activity to achieve important health benefits. This finding further supports the notion that both people with MS together and their caregivers warrant attention for physical activity interventions.

The third manuscript reports the findings of a cross-sectional survey that identifies the most pressing needs for community resources to support physical activity participation among people with moderate-to-severe MS disability and their caregivers, determinants of perceived need and barriers to sole – versus co-participation in physical activity. Seventy-eight people with MS and 46 caregivers participated in this study. Three need items were prioritized by both people with MS and their family caregivers. These items include the need for: 1) information about available resources to support physical activity participation; 2) programs that support joint participation of people with MS and family caregivers in physical activity; and 3) programs that have total costs of participation, which are affordable. A broad range of factors (i.e., education, living situation, type of community, marital status and income, as well as comorbidity status) was significantly associated with one or more of these need items. Although there was variability in the perception of barriers to sole– versus co– participation between people with MS and their caregivers, several modifiable impairment-related, personal and logistical factors were identified by both groups.

Chapter six consolidates the dissertation document by synthesizing the findings and examining the implications of this work for the design and implementation of dyadic physical activity interventions for people affected by moderate-to-severe MS disability and the caregivers who support them. The limitations of this work and the recommendations for future research are addressed before giving the final conclusions.
1.3 References


Chapter 2 Literature Review

2.1 Introduction

The overarching goal of this chapter is to introduce and evaluate the key topics about participation in physical activity among people affected by moderate-to-severe MS disability (i.e., individuals who have the disease and those who support them). The chapter is divided into three sections. The first section provides an overview of MS and highlights the disease impact on the people who have it and their family caregivers. The second section discusses physical activity participation and illustrates the complexity of promoting regular participation among caregiver care-recipient dyads. The gaps in knowledge in this area are also highlighted. The third section discusses the theoretical framework and the overarching methodology used within this dissertation.

2.2 Overview of MS

2.2.1 Prevalence, Etiology and Pathogenesis of MS

MS is one of the most common neurodegenerative conditions with symptoms first presenting in young adults 20-40 years old (mean age of onset 32.3 years) who are at the peak of their career and family development \(^1\,^2\). Conservative estimates report that over 2.5 million people are living with MS globally \(^3\) and women are almost three times more affected than men \(^4\). Approximately 100,000 people are currently living with the disease in Canada \(^3\) and this number is projected to rise to over 130,000 by 2031 \(^5\).

Researchers have also reported that the age of peak prevalence of MS is at an all-time high, with peak rates at 64-67 years \(^5\). The prevalence estimates of MS in older Canadian adults (≥ 55 years old) range between 250 and 900 cases per 100,000 people compared with 50 and 800 cases per 100,000 people in young to middle-aged adults \(^5\). These figures show that there is an increasing number of older adults with MS than ever before, and this trend is expected to continue over the next few decades \(^6\).
The etiology of MS and its pathogenesis are not yet fully understood. However, MS is thought to be an immune-mediated disease that is triggered by an environmental agent in genetically susceptible people. The immune, environmental and genetic factors associated with MS are disused below.

2.2.1.1 Immune factors associated with MS

The pathologic hallmark of MS is the spatiotemporal distribution of sclerotic plaques or lesions within the CNS as a result of multiple underlying processes that cause tissue damage. The disease process can be divided into two phases. In the early inflammatory phase, immune cells including activated T cells, B cells, and macrophages infiltrate the blood-brain barrier (BBB). The entry of these infiltrates compromises the integrity of the BBB, promoting axonal demyelination. In this first phase, the axons are able to re-myelinate and restore functional nerve transmission. When remyelination occurs, the inflammatory response subsides and the clinical symptoms diminish.

The disease gradually progresses into a second phase, which is characterized by neuroaxonal destruction and metabolic changes. The main targets of these changes are the myelin sheaths, oligodendrocytes, and neurons in the brain, spinal cord and optic nerves. The recurring attack on these structures translates to permanent damage in which remyelination does not occur and there is symptom progression. The resulting disruption of neuronal signaling correlates with physical disability in people affected by the disease.

2.2.1.2 Genetic factors associated with MS

The genetic component of MS is complex and may involve many susceptibility genes. Several alleles of the major histocompatibility complex (MHC) and other non-MHC alleles have been associated with an increased risk of MS. The HLA class II and I genes are particularly relevant modifiers of disease risk: variants of class II genes encode products that present antigens to CD4+ T lymphocytes, and class I
products present antigens to CD8+ lymphocytes. In particular, the class II variant HLA-DRB1*15:01 has a strong association with increased disease risk (odds ratio ~3).

The genetic link to MS is further supported by epidemiological studies showing a relatively high incidence in monozygotic twins (25%) compared with dizygotic twins (4%) irrespective of location. Similarly, studies on the heritability of MS have estimated that a sibling of an individual with MS has an almost 17-fold increase in disease risk. However, recent population-based studies suggest that a sibling’s relative risk is only increased by approximately 7-fold. This finding indicates a much lower importance of genetic predisposition than previously thought, and suggests that non-genetic influences including environmental factors may play a role in disease development.

### 2.2.1.3 Environmental factors associated with MS

Several environmental factors have been suggested to be involved in triggering the autoimmune response in genetically susceptible individuals. These factors include cigarette smoking, viruses, infections, diet, sun exposure and vitamin D status, pollutants, and toxins. However, no single environmental factor has been identified as the disease trigger. The contribution of multiple environmental and genetic factors in the development of MS makes it a complex multifactorial disease that is extremely challenging to understand and treat.

### 2.2.2 Disease Course

The MS disease course is often classified into one of four categories. The most commonly reported disease course is relapsing-remitting MS (RRMS) and approximately 80% of newly diagnosed cases fall into this category. People with RRMS experience intermittent episodes of relapses, which are associated with inflammatory demyelinating attacks. These attacks are followed by periods of remission, during which fewer or no symptoms occur and remyelination of the damaged axons takes place.
Secondary progressive MS (SPMS) is characterized by an increase in severity of symptoms with an incomplete recovery of function and progressive disability. The progressive disability can occur with or without relapses and is associated with irreversible axonal damage. Approximately 20-30% of the MS population has SPMS.

When MS is progressive from the onset, it is classified as primary progressive MS (PPMS) and it accounts for 5-10% of MS cases. People diagnosed with PPMS experience a steady increase in disease progression interspersed with occasional disease remission involving temporary mild improvements. This form of MS has more lesions in the spinal cord than in the brain with greater effects on mobility. People with progressive-relapsing MS (PRMS) have a similar disease presentation as individuals with PPMS but they also experience acute relapses without full recovery. This disease course is relatively uncommon affecting only 5% of people with MS but results in high mortality rates.

### 2.2.3 Measuring Disease Progression

Disease progression and accumulation of disability vary depending on the disease course, and other clinical and demographic characteristics including age, sex, symptoms, and the degree of recovery from the first relapse, time to a second relapse, as well as the number of relapses in the first five years after disease onset. Disability benchmarks based on the Expanded Disease Severity Scale (EDSS) developed by Kurtzke have been the most widely used to assess neurological impairment and classify the pattern of disability progression in MS. The EDSS is an ordinal measure scored on a scale ranging from 0 (no neurological impairment) to 10 (death due to MS). Scores on the EDSS can be categorized into minimal, moderate and severe disability. An EDSS score of 3 suggests minimal disability, a score of 6 represents moderate disability, where a mobility aid is required, and severe disability is reserved for scores of 7 and above, where people are mainly wheelchair users or bed bound. Scoring on this scale is based on the
neurological assessment in eight functional systems (FS), which include pyramidal, cerebellar, brainstem, sensory, bowel and bladder, visual, mental and other functions.

Despite the widespread use of the EDSS in clinical practice and research, it remains widely criticized. One of the limitations of the EDSS is the lack of reliability due to inconsistencies with reporting ambulatory distances and the inclusion of subjective information; both of which are needed to decide the level of disability on the scale. Similarly, the use of the terms “mild”, “moderate” and “severe” in the assessment items could have different meanings to different assessors, contributing to variability in the scoring. The EDSS has also been criticized for its use of a non-linear scale. People with MS will progress faster from steps one through five than between steps five through seven. As a result of the non-linearity, many cross-sectional studies show a bimodal distribution of scores. Other researchers argue that the scale does not reflect wider aspects of disability such as work, leisure and activities of daily living (ADLs) nor does it capture changes in cognitive or visual systems. However, the EDSS was originally developed as a neurological tool to assess MS-related impairment and not intended to measure these broader aspects of life. Finally, the EDSS requires specialized training to complete the analysis of the FS. Together, these limitations suggest that the EDSS may not always be appropriate or cost-effective to use in some clinical and/or research settings.

The Disease Steps (DS) was developed as a simpler tool for assessing disease severity in MS. The DS is scored on an ordinal scale of 0-7, where 0 indicates functionally normal with no limitations on activity or lifestyle and 7 is used for people whose disability cannot be classified as 0-6. A high correlation has been reported between the EDSS and DS ($r = 0.944$). In comparison to the EDSS, the DS has several advantages: 1) it is quick and easy to administer; 2) people with MS show a uniform distribution among different steps, whereas a bimodal distribution occurs with the EDSS; and 3) it has a lower inter-rater variability. However, the DS still requires classification of disability based on ambulation and a history of neurologic examination.
In response to the limitations of the previous measures, the Patient Determined Disease Steps (PDDS) was developed as a surrogate for the EDSS by researchers associated with the North American Research Committee on MS (NARCOMS) \(^{41}\). The PDDS is a patient-reported outcome measure of MS disability in which scores range from 0 (normal) to 8 (bedridden). The PDDS also allows classification of disease severity into mild, moderate or severe disability. Although the PDDS is a self-reported measure, which has the potential of subjectivity and inaccuracy of classification, scores from the PDDS have been reported to be linearly and strongly related with EDSS scores \(^{42-44}\). Furthermore, the PDDS is simple and easy to administer and does not require neurological examination or training to use, making it cost-effective in some clinical and/or research settings. Since its development, the PDDS has been included in various MS-related research, including fatigue management \(^{45,46}\), employment \(^{47}\), comorbidities \(^{48}\), falls prevention \(^{49}\) and physical activity assessment and intervention \(^{50,51}\). This dissertation uses the PDDS to identify people with MS who have moderate-to-severe disability with a score of 3 (gait disability) to 6 (needing bilateral support to ambulate) on the scale.

### 2.2.4 Symptoms associated with and the impact of MS

MS can result in a wide range of symptoms based on the location and severity of the CNS damage \(^{11}\). These symptoms may include fatigue, gait impairment (mobility and balance problems), heat sensitivity, muscle weakness and spasms, bladder and bowel dysfunction, spasticity and ataxia, cognitive deficits, vision complaints, anxiety and depression \(^{11}\). Importantly, fatigue, gait impairment and cognitive deficits are three of the most common, disabling, and poorly managed problems experienced by people with MS. For instance, 70 – 90% of people with MS experience fatigue, and for the majority of these individuals, it is their most challenging symptom \(^{52}\). Gait impairment, particularly mobility problems, is experienced by nearly half of the MS population within one month of diagnosis and this proportion increases to 93% within 10 years of diagnosis \(^{53}\). Upwards of 50% of people with MS experience cognitive deficits, which primarily manifest as slowed cognitive processing speed and impaired learning and memory \(^{54}\).
MS symptoms may interfere with a person’s ability to complete basic and instrumental ADLs and are independent predictors of quality of life among people who have the disease. For instance, balance problems have been associated with an increased fall risk. Studies indicate that in a 3-month period, more than 50% of people with MS will have experienced at least one fall and 12-58% will have had a fall that results in an injury. With the high risk of injurious falls, it is not surprising that many people with MS report a fear of falling and reduce their participation in daily activities due to this fear. Furthermore, planning social activities outside the home can be difficult in the presence of mobility impairment and overwhelming fatigue that cannot be alleviated with rest. The impact of fatigue and mobility impairment on employment status and the ability to complete tasks within the workforce has also been highlighted. In a Canadian study involving 602 people with MS, 66% were unemployed, and 39% of these individuals cited fatigue as one of the main contributing factors.

Moreover, cognitive processing, memory and concentration can all be impaired during periods of fatigue, which in turn, may contribute to the challenges people with MS face in the workplace. Recently, van Asch and colleagues reported that mobility problems had significantly affected the working life of about 72% of people with MS. Sixty-one percent of these individuals had not worked at all in the last six months and about 40% had been absent from work for an average of 16 days. More than half of the participants in this study also reported lost earnings due to mobility impairment.

In addition to the economic implications for individuals with MS, the disease also has significant costs for the Canadian healthcare system and society as a whole. A recent micro simulation study in Canada reported that the out-of-pocket expenses incurred by people with MS was approximately $84 million in 2016, with a projected increase of 74% by 2031. This study further reported that the total healthcare sector costs for people with MS in 2016 was ~$1 billion. Other researchers have shown that MS costs the Canadian economy approximately $30,836/person, $46,622/person and $77,981/person annually for people with mild, moderate and severe disability respectively. Thus, MS is one of the most costly...
neurological diseases and among direct all-cause medical costs for chronic health conditions, MS has the second highest costs after congestive heart failure.

The MS disease process is also associated with the accumulation of irreversible disability over time among affected individuals. It is estimated about 50% of people with MS will have moderate disability or worse (i.e., PDDS ≥ 3 or EDSS ≥ 6) within 15-20 years after the onset of the disease and this proportion increases to 75% after 45 years. Furthermore, researchers have shown that about 23-26% of people with MS are either non-ambulatory or have significant walking limitations that require support for gait, reflecting a higher level of disability. Because of the progressive worsening of disability, individuals with moderate-to-severe disability may also require more specialized supports to manage daily activities and associated life roles. For instance, 83% of people with MS who have significant mobility impairment reported needing assistance to fulfill their household responsibilities while 37% required assistance with personal care.

People with MS, especially those with more severe disability, may also present with differences in physiological characteristics in comparison to their healthy, aged-matched counterparts. For instance, studies have shown that aerobic capacity and cardiorespiratory fitness, expressed as maximum oxygen consumption (VO\textsubscript{2}max), is about 30% lower among people with MS compared with healthy controls. The difference in aerobic capacity may be related to a lowering of the maximal heart rate (HR\textsubscript{max}) among people with MS since the VO\textsubscript{2}max is closely connected with HR\textsubscript{max}. Previous studies have also reported significantly lower HR\textsubscript{max} in people with MS versus healthy controls. Together these findings suggest that individuals with higher levels of disability may have complicated symptom profiles and substantial activity limitations, as well as participation restrictions. These individuals represent a unique subset of the MS population and are different from those with mild MS disability. Therefore, evidence from people with lower MS disability levels may not be fully applicable to those with moderate-to-severe disability.
2.2.5 The Role of Caregivers

Despite leading to significant disability, MS has only minimal impact on life expectancy, as people with MS can expect to live only 2-5 years less than their age – and sex – matched counterparts without the disease. Overall, Canadians life expectancy is about 79 years for men and 83 years for women. These figures suggest that the majority of individuals who are diagnosed with MS in their early 20s are likely to live with the disease for ≥ 50 years. As a result, they may have to live a significant period of their lives coping with substantial disability relative to their counterparts who do not have MS.

The task of providing assistance to compensate for the resultant limitations in ADLs for people with MS falls primarily on their family caregivers. Family caregivers have been described as “any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for an adult with a chronic or disabling condition”. MS caregivers are predominantly spouses, who provide 70-80% of the care for their loved ones with the disease. Family caregivers, especially of those individuals with higher levels of MS disability, may spend 10 or more hours/day providing a range of services for their loved ones including personal care, meal preparation, transportation, housework, mobility, dressing and recreation. With normal-to-near normal life expectancies in the MS population, the reliance on caregivers is expected to grow and an increasing number of caregivers may need to provide complex care to adults with MS living at home.

Although there are positive aspects of providing care to a person with MS, the negative impact on caregivers’ health is often great due to the emotional and physical dependency that develops among their care-recipients as the disease progresses and disability accumulates. For instance, MS caregivers are more likely than the general population to report poor health-related quality of life. Furthermore, in comparison to caregivers of people with other chronic neurological conditions, such as Alzheimer’s disease, MS caregivers experience a higher level of activity limitations, more emergency department
visits, and hospitalizations \(^{116}\). Collectively, these issues may reflect caregiver burden, which has been
described as the impact of the caregiving role on the physical health and psychosocial wellbeing of the
caregiver \(^{106,117,118}\).

Caregiver burden has been related to the severity of symptoms and level of disability of the person with
MS receiving care \(^{119,120}\). For instance, survey data \(^{82}\) indicate that among 203 caregivers assisting a
person with MS with mobility impairments, 40% said that they felt burdened by their care-recipients’
 mobility issues, and 57% were depressed about this impairment. In addition, 34% of the caregivers
reported that the mobility impairment of their care-recipients had a negative impact on their own quality
of life, while 84% said it affected their work life resulting in reduced personal income. Other adverse
effects of care-recipient’s mobility impairment on caregiver employment were also reported including
being absent from work (32%), the need to reduce workload and schedule (15%), requiring workplace
accommodations (16%) and going off work completely for a period of time (10%). Importantly, the
impact of care-recipients’ mobility impairments on the caregivers are similar to those reported by people
with MS themselves in previous research \(^{53}\), further supporting the notion that the impact of MS extends
beyond the individual primarily affected by the disease to his/her family caregivers. Taken together, these
studies suggests that there is an interdependent or dyadic component to the caregiving role, and points to
the need to consider the health of the person with MS and their caregiver as an interdependent unit rather
than each in isolation.

2.3 Managing some of the Disease Impact through Physical Activity Participation

Despite extensive and ongoing research in MS pathology and treatment, there is still no cure for the
disease. However, pharmaceutical therapies including disease-modifying drugs represent the first line of
treatment for MS \(^{121}\). Despite the promise of these medications and their success in reducing the
development of new lesions, there is growing recognition that these drugs are only minimally effective in
slowing down the eventual progression of neurological disability in MS\textsuperscript{121-124}. This situation underscores the urgent need to develop alternate strategies that can reduce the disease impact, potentially to a greater extent than pharmacological interventions alone, for people living with the disease and those who support them. One of the rehabilitation strategies to manage some of the disease impact on both people with MS and their caregivers is increasing participation in physical activity.

### 2.3.1 Physical Activity in MS

Physical activity is defined as any bodily movement that involves contraction of the skeletal muscles to produce an increase in energy expenditure above resting levels, and may include leisure-time activities, household chores, occupational work, transportation and sports-related activities\textsuperscript{125,126}. Exercise on the other hand, is one component of physical activity that involves accumulating bouts of planned and structured activities that are repeatedly performed over a prolonged period of time with a specific goal of improving or maintaining physical fitness\textsuperscript{127}.

Historically, people with MS were told not to participate in physical activity because of acute transient problems with mobility, weakness and fatigue after exercise\textsuperscript{128}. However, current research challenges this view and demonstrates that exercise is safe and well-tolerated by people with MS\textsuperscript{102,129}. For instance, a study examining the effects of an acute bout of combined (i.e., aerobic, resistance and stretching) moderate intensity exercise found no significant change in fatigue or general physical function immediately after and 24 hours post exercise\textsuperscript{130}. Although the authors reported a temporary increase in participants’ sensory symptoms immediately after exercise, these symptoms returned to baseline within an average time of 18.6 minutes post exercise. Furthermore, a recent systematic review\textsuperscript{131} demonstrated that exercise does not increase relapse risk. The relative risk of relapse was 0.67 for exercise training compared with non-exercising controls with MS, while the risk of adverse events for exercise training was 1.67 compared with controls. Importantly, the risk of adverse effects was comparable to risk levels
reported in healthy populations. In addition, individuals stratified as most active in a study involving a large sample of people with MS (n= 632; mean ± SD EDSS =3.0±1.8) reported the fewest number of relapses 132.

Consequently, physical activity has received recent attention as an alternative behavioral approach for managing the impact of MS 133. The emergence of physical activity as an important component of comprehensive MS care has been accompanied by the development of The Canadian Physical Activity Guidelines for MS 134. The guidelines recommend at least 30 minutes of moderate intensity aerobic activity twice a week for adults aged 18-64 years who have mild-to-moderate MS disability. Although this recommendation is less than the ≥150 minutes/week in the physical activity guidelines for the general population 135, both guidelines include strength training exercises for major muscle groups twice a week.

Researchers have sought to compare the physical activity levels of people with MS to the general adult population and those with other chronic conditions. However, studies have typically not distinguished between individuals with mild-to-moderate versus moderate-to-severe MS-disability 136-140. Despite this limitation, we can draw on the well-established body of literature involving people with mild-to-moderate MS-disability as evidence for physical inactivity in the general MS population including those with moderate-to-severe disability. For instance, in a large sample of people with MS, less than 25% reported participating in moderate to vigorous physical activity (MVPA) 141. Several studies using self-report measures of physical activity have also reported people with MS to be less active than non-MS controls matched for age, sex, height and weight 142-145. For example, Nortvedt et al., 144 reported that people with MS are less physically active than healthy controls without MS, as well as people with other chronic disease conditions such as angina pectoris, asthma and diabetes. Similar findings have been made with objective measures of physical activity 89,143,146,147.
Lower levels of physical activity have been associated with greater neurological impairment and disability among people with MS. Disability progression over a period of six months was associated with a concurrent reduction in physical activity behavior. Collectively, this research indicates that physical activity levels are lower in people with MS who have greater impairment and that the progressive accumulation of disability results in less participation in physical activity. Sandroff and colleagues recently proposed a model (Figure 2-A) describing the relationship between MS, physical inactivity and physiological and functional impairment. This model hypothesizes that MS disease processes and symptoms result in reduced ability to participate in physical activity. Physical inactivity, in turn, initiates aerobic and muscular deconditioning and ultimately worsening of MS symptoms. Physiological deconditioning results in mobility limitations, which in a cyclical manner further limits ability of people with MS to participate in physical activity. This process yields a cycle of associations between physical inactivity, deconditioning, and continual worsening of MS, as well as accrual of disability that develops over time. Reduced participation in physical activity further places people with MS at an increased risk of comorbid health conditions. The most common comorbidities reported among people with MS include hypertension, hyperlipidemia and chronic lung disease. Vascular comorbidities in MS have been further associated with an increased risk of disability progression.
Figure 2-A. Cyclical model of physical inactivity, physiological deconditioning, and worsening of multiple sclerosis over time

2.3.2 Physical Activity in MS Caregivers

Unfortunately, there is no published research on physical activity levels of MS caregivers. Considering the limited evidence, we draw on the general caregiving literature to suggest that increasing responsibilities and the chronic stress of caregiving may impede physical activity participation among MS caregivers. Indeed, previous observational studies have consistently shown that caregivers do not engage in recommended physical activity levels and that they engage in less physical activity when compared with non-caregivers. For instance, Beesley et al. demonstrated that approximately 50% of caregivers of people with cancer did not meet public health recommendations for physical activity. In addition, Fredman and colleagues reported that caregivers were less likely to engage in leisure-time physical activity than non-caregivers. Furthermore, caregivers who spend the most time providing care are the least likely to be physically active.

2.3.3 Benefits of Physical Activity

There is evidence supporting the benefits of physical activity on health outcomes among adults with MS, although the effects of aerobic exercise have been studied more extensively than resistance training. Improvements in physiologic metrics such as VO2 max and functional capacity have been reported in studies evaluating the effects of moderate intensity aerobic training for 30-60 minutes 2-3 times a week in people with MS. Studies evaluating the effect of resistance exercise training programs in MS have also demonstrated increases in muscle fiber cross-sectional area, muscle strength and functional capacity. Furthermore, several systematic reviews and meta-analysis have shown that physical activity is beneficial for fatigue, depression, mobility, and quality of life among people with MS.

Unfortunately, there is less consistent evidence in the MS literature for the effect of physical activity on other important outcomes, such as cognitive function. A recent systematic review identified nine studies...
examining the effect of long-term exercise training on cognition. This review determined that the current evidence involving exercise training was too limited and conflicting to provide any definitive conclusions. However, there is cross-sectional evidence of independent associations between MVPA (min/day), cardiorespiratory fitness and structural magnetic resonance imaging (MRI) outcomes including cortical and subcortical gray matter volumes among people with MS. These findings suggest a potential protective role of physical activity for preserving brain structure and this could result in the preservation of motor and cognitive functions in MS.

Despite the promising evidence, people with moderate-to-severe MS disability have been typically excluded from research examining physical activity interventions. In addition, the majority of physical activity interventions in MS have been individually oriented (i.e., focusing on people with MS only). No studies have focused on physical activity participation of MS caregivers. Given the vital role of MS caregivers and the significant impact of caregiving on their lives, it is important to identify strategies, including physical activity, that can mitigate the negative effect of caregiving and improve the overall quality of life of MS caregivers.

Although there is very limited evidence for the benefits of physical activity in MS caregivers, we can glean understanding from the general caregiving literature. Previous studies of caregivers have reported improvements in walking endurance, strength, and balance in response to physical activity interventions. Beyond these benefits, caregivers who engage in regular physical activity are better able to cope with the physical and mental challenges associated with caregiving thereby delaying institutionalization of their care-recipients. Several clinical trials and systematic reviews have shown that the negative psychological impacts of caregiving, including depression, anxiety, stress, anger and burden could also be alleviated with physical activity. Taken together, this research suggests that the benefits of physical activity can be extended to caregivers of people with MS as well. Given that people with MS and their
caregivers often react to and cope with the disease as an interdependent unit, a dyadic approach that focuses on both partners together may be beneficial for designing physical activity interventions.

2.4 Theoretical and Methodological Frameworks

2.4.1 Theoretical Framework

We considered three coping theories as possible theoretical framework for this dissertation work, including 1) Transactional Theory of Stress developed by Lazarus and Folkman; 2) Systemic Transactional Model developed by Bodenmann; and 3) Developmental Contextual Coping Model developed by Berg and Upchurch. In brief, the Transactional Theory of Stress focuses on everyday stress and conceptualizes the experience of stress and coping as an individual phenomenon. Thus, it does not take into account the relational and interdependent process that occurs between partners in close relationships as they cope with stress. The Systemic Transactional Model expands this individualistic orientation by suggesting that one partner’s experience of stress is not limited to him/herself, but affects the experience and wellbeing of the other partner; therefore coping with stress is a dyadic phenomenon. Despite the dyadic orientation, this theory does not take into account stressors that may occur when one partner is diagnosed with a chronic disease such as MS. Berg and Upchurch proposed a Developmental Contextual Coping Model that is theoretically close to the Systemic Transactional Model regarding dyadic conceptualization of stress and coping, but enlarges this model in the context of severe stressors that occur as partners deal with the different stages of chronic diseases. Based on these features, the Developmental Contextual Coping Model was chosen as a theoretical framework to guide this dissertation work. An in depth discussion of the model is provided in the proceeding sub-section.
The Developmental Contextual Coping Model posits that dyads affected by chronic disease may experience disease-related (e.g. initial symptom identification, illness severity, ongoing treatment) and caregiving-related (e.g. providing ongoing caregiving services such as assistance with daily activities, personal care) stressors. These disease- and caregiving- related stressors can affect the wellbeing of the partners individually and differently, as well as collectively as a dyad, and the quality of their relationship. The model goes further to suggest that dyads with chronic diseases often cope with these stressors across the lifespan (i.e., young, middle-aged and older adult dyads) and different stages of the disease as it unfolds. This conceptualization of developmental and temporal coping may be particularly salient in MS, where the dyads may need to deal with the psychological, practical and relationship consequences of living with the disease, and the additional expectation of a future characterized by progressive disability. Thus, the model perceives stress and coping as a social process rooted in close relationships, where one partner’s experience is not limited to him/herself, but affects the experience of the other partner as well.

The Developmental Contextual Coping Model describes four strategies that may be used to cope with disease- and caregiving- related stressors among dyads affected by chronic diseases. These strategies exist along a continuum of partner involvement, from under-involvement to over-involvement. The strategies include: 1) uninvolved coping, which is when each partner is coping alone with their individual stressors; 2) supportive coping, which describes the provision of physical, instrumental or emotional support from one partner to the other person; 3) collaborative coping, which extends beyond the provision of social support to a situation whereby both partners actively negotiate aspects of their shared experience and take equal responsibility for engaging in practical coping strategies (e.g., joint problem solving and goal setting for physical activity); and 4) control strategies where one partner, usually the caregiver, underestimates the abilities of and dominates the actions of the other partner by taking charge and telling
the other person what to do. According to the model, dyads who can jointly appraise the disease as a “shared disease”, pull resources together and engage in collaborative coping strategies will be better able to confront and overcome the challenges of living with and managing chronic diseases.\(^{192-194}\)

Research investigating the Developmental Contextual Coping Model has also shown that collaborative coping strategies contribute to beneficial health-related outcomes including reduction in self-reported heart failure symptoms\(^{195}\) and cortisol levels\(^{196}\), as well as improvement in metabolic control\(^{197}\) and quality of life\(^{198}\) among dyads affected by various chronic diseases. In particular, joint participation in physical activity may improve muscle strength, physical function and psychological health, as well as exercise adherence for both partners, and caregiver coping skills in diabetes, cancer and dementia\(^{199-204}\). Hackney and Earhart\(^{205}\) further compared the effects of individual and dyadic physical activity (non-partnered and partnered tango dancing) on balance and mobility in 39 people with mild-moderate Parkinson’s disease (Hoehn and Yahr stages I-III). After 10 weeks of 1-hour dance sessions twice per week, the authors showed that both groups significantly improved on the Berg Balance Scale, comfortable and fast-as-possible walking velocity, and cadence. The improvements were maintained one month after completing the dance intervention. Of importance, the participants in the partnered intervention group expressed more enjoyment and greater interest in continuing with the dance classes after the study period.

Despite the promise of dyadic physical activity interventions and models such as the Developmental Contextual Coping Model, no studies to date, have capitalized on the potential benefits of including both people with MS and their caregivers in the same physical activity intervention. Thus, the model conceptually informed this dissertation in two ways. First, it promoted a shift away from the individualistic orientation that has traditionally dominated previous physical activity research in MS. The shift in turn, provided a dyadic lens that acknowledged the dynamic interaction that occurs between people with MS and their caregivers, as they enact behavioral efforts towards managing the impact of the
disease. Second, it maintained our commitment to exploring experiences of and identifying issues related to physical activity participation at the level of the dyad rather than the individual.

Although the Developmental Contextual Coping Model has a unique perspective on dyadic coping and adjustment to chronic diseases, it does not provide a specific process guide to healthcare providers interested in moving caregiver care-recipient dyads from the negative dyadic coping to the collaborative coping end of the continuum. In addition, the model lacks information on the mechanisms by which dyadic coping may influence uptake and/or maintenance of collaborative behavioral strategies including physical activity. Finally, it has little utility for guiding the various processes involved in hypothesis generation and development of dyadic physical activity interventions. This limitation is important because the process of gathering key preliminary evidence strengthens and informs the development, evaluation and final implementation of any intervention. Thus, to overcome some of the limitations of the Developmental Contextual Coping Model, this dissertation incorporated an additional methodological framework to provide a clearly defined step-by-step guide for gathering preliminary evidence to inform the development a dyadic physical activity intervention in MS. This methodological framework will be discussed in detail in the proceeding sub-section.

2.4.2 Methodological Framework

Over the last three decades, various methodological approaches to needs assessment have been identified and implemented with varying degrees of success. Some of the methodological approaches include: 1) the Logic Model; 2) the Three-Phase Model; 3) Community Building; 4) Participatory Approaches; and 5) Concerns Report Methodology. Whilst it is beyond the scope of this dissertation to offer an in-depth discussion of the available approaches to needs assessment, it is necessary to describe the Concerns Report Methodology and highlight the rationale for selecting this methodology.
The Concerns Report Methodology was developed in 1980 by Fawcett and colleagues in partnership with independent living agencies serving people with disabilities. The Concerns Report Methodology is a systematic participatory action-oriented research process to needs assessment that includes agenda setting, capacity building and empowerment for community change among individuals who share a common issue. It involves stakeholders from constituent groups collaborating with the needs assessment team to identify and prioritize community needs, issues and concerns. One of the interesting and unique features of the Concerns Report Methodology is the survey (see Table 2-A), and how the way it is structured produces a prioritization of community needs. The findings generated through this process can then be used in the development and planning of appropriate resources to address the most pressing needs of the community. Since its development, the Concerns Report Methodology has been used by researchers interested in building community-generated research agendas with various groups including low income families in rural communities, people with physical disabilities and traumatic brain injury, Hispanic immigrants and older individuals. There are five basic phases of the Concerns Report Methodology process (see Table 2-A). It is important to note that phases one through three identify and prioritize needs, issues and concerns, while phases four and five focus on planning actions and solutions, which can take several years.

The Concerns Report Methodology was selected for three important reasons. First, by using a systematic and simple consumer-driven needs assessment methodology, we wanted to be able to involve MS rehabilitation professionals, people with MS and their caregivers in exploring relevant physical activity-related issues. Second, we anticipated that the early involvement of people with MS and their caregivers in the decision-making may increase the likelihood that they will remain actively involved in the entire research process even beyond this dissertation. Finally, we anticipated that the process of getting people with MS and their caregivers to think about and identify their physical activity related concerns
may increase the likelihood that they take ownership of the research, and set the agenda for addressing the
needs they see as most important \textsuperscript{223}. 
Table 2–A. The phases of the Concerns Report Methodology

<table>
<thead>
<tr>
<th>Phase</th>
<th>Description</th>
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<tbody>
<tr>
<td>1. Focus Groups</td>
<td>Focus groups are conducted with representatives of the population being studied to identify community values and general needs.</td>
</tr>
<tr>
<td>2. Development of a structured survey</td>
<td>A working group of key informants is assembled to actively contribute to the development of a structured survey using findings from the focus groups. Each item in the Concerns Report domain of the survey has an importance dimension (scored on a scale ranging from 1 ‘not important’ to 4 ‘very important’) and a satisfaction dimension (scored on a scale ranging from 1 ‘not satisfied’ to 4 ‘very satisfied’);</td>
</tr>
<tr>
<td>3. Survey dissemination and analysis</td>
<td>The survey is disseminated as broadly as possible to allow as many members of the community to participate. Analyzing the survey involves the calculation of a need index for each item. The Need Index is calculated as follows: The proportion of respondents who state that an item is very important is calculated; The proportion of respondents who state that they are very satisfied with the item is calculated; and Need Index = proportion very important – proportion very satisfied. The Need Index allows the needs assessment team to be able to identify community needs and concerns in order of priority. Responses are classified based on the Need Index into: 1) needs and concerns - survey items that a majority of respondents rate as high in importance and low in satisfaction; and 2) strengths - survey items that a majority of respondents rate high in importance and in satisfaction.</td>
</tr>
<tr>
<td>4. Public meetings and action committees</td>
<td>A “public meeting” is convened to discuss the results of the survey with community members and generate ideas for further action to address needs and concerns. An action committee is set up to plan and implement programs or services that address the needs of the community</td>
</tr>
<tr>
<td>5. Monitoring and feedback</td>
<td>Monitoring of the committees and dissemination of the final report throughout the community</td>
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2.5 Summary

This chapter has provided the background and justification for conducting a needs assessment to determine if there is sufficient evidence to support the development of a dyadic physical activity intervention in MS. The literature to date indicates the following:

1. The number of people living with MS in Canada is projected to rise from about 100,000 to over 130,000 by the next decade.
2. The etiology and pathogenesis of the disease are not yet fully understood. However, immune, environmental and genetic factors have been implicated.
3. MS symptoms are widely varied, can interfere with ability to complete ADLs and are independent predictors of quality of life.
4. About 50% of people with MS will have moderate disability or worse within 15-20 years after disease onset and this proportion increases to 75% after 45 years.
5. Individuals with moderate-to-severe MS represent a unique subset of the MS population because of their complicated symptom profiles, significant activity limitations and participation restrictions, as well as need for specialized supports and significant costs associated with their care.
6. Family caregivers, particularly spouses, provide the majority of the support needed by people with MS. With normal-to-near normal life expectancies in the MS population, the reliance on caregivers is expected to grow.
7. There are substantial negative impacts on caregivers’ health and quality of life due to the emotional and physical dependency that develops among their care-recipients as the disease progresses and disability accumulates.
Physical activity may reduce the impact of MS symptoms including fatigue, mobility impairment and balance problems on activities of daily living and quality of life of people with the disease.

Physical activity may also reduce the impact of care-recipient’s chronic disease on the health and quality of life of family caregivers, although this research is, to a large extent, unprecedented in the MS caregiving literature.

Few studies have focused on physical activity in people with moderate-to-severe MS-disability and no studies to date have capitalized on the potential benefits of including both caregivers and people with moderate-to-severe MS-disability in the same dyadic physical activity intervention.

The Developmental Contextual Coping Model suggests there may be an important opportunity in extending this research to people affected by moderate-to-severe MS-disability and the family caregivers who support them.

The Concerns Report Methodology provides a methodological framework to guide the research activities that were conducted as part of this dissertation work.

This direction of research warrants new research investments and a theoretically driven intervention development process, which begins with a comprehensive needs assessment. Therefore, the overarching goal of this dissertation was to determine if there is sufficient evidence to support the development of a dyadic physical activity intervention for people with moderate-to-severe MS-disability and family caregivers.

The specific aims are to:

1. Describe the shared perspectives of people with moderate-to-severe MS disability and their family caregivers about physical activity (manuscript 1);

2. Determine physical activity pattern interdependence within dyads affected by moderate-to-severe MS disability (manuscript 2); and
3. Identify the needs, issues and concerns of the target groups regarding community resources to support physical activity participation (manuscript 3).
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Chapter 3 Understanding leisure-time physical activity: Voices of people with MS who have moderate-to-severe disability and their family caregivers

**Citation:** Fakolade, A., Lamarre, J., Latimer-Cheung, A., Parsons, T., & Finlayson, M. 2017

Understanding leisure-time physical activity: Voices of people with MS who have moderate to severe disability and their family caregivers. Health Expectations 00: 1-11. doi: 10.1111/hex.12600.

The accepted version of the manuscript is provided and is presented according to the journal’s guidelines.

**Funding information:** A. Fakolade received research funding from The Canadian Disability Participation Project (CDPP). The CDPP is supported by the Social Sciences and Humanities Research Council of Canada under grant number 895-2013-1021 (to Latimer-Cheung, Co-investigator). This work was also supported through a Doctoral Studentship Award from the Multiple Sclerosis Society of Canada, (Grant/Award Number: EGID 2022) to A. Fakolade.
3.1 The contribution of manuscript 1 to the dissertation

The first manuscript contributes to the overarching goal of the dissertation by exploring the co-constructed experiences of physical activity from the perspectives of people with moderate-to-severe MS disability and their caregivers. By involving people with MS together with their caregivers as co-participants in this study, a collaborative partnership was created between the participants and the researchers, where the dyads identified unique issues, concerns, and needs related to their physical activity participation, and discussed possible solutions that acknowledged current community resources. In this way, the first manuscript helped direct the research to areas where deficiencies were perceived, and formed the building blocks upon which subsequent manuscripts within the dissertation were built.

3.2 Sections included in and appendices associated with this chapter

Sections 3.3 to 3.9 are included in the published manuscript Health Expectations 00: 1-11. doi: 10.1111/hex.12600. The following appendices contain information associated with this chapter: Appendix A: Ethics approval; Appendix B: Letter of information and consent form; Appendix C: Focus group guide; Appendix D: Demographic and clinical characteristics questionnaire for people with MS and their caregivers.
3.3 Abstract

**Background:** Physical activity is beneficial for all people, yet people affected by multiple sclerosis (MS) find regular physical activity challenging. These people may include individuals with the disease who have moderate-to-severe disability and their family caregivers. For researchers and clinicians to effectively promote physical activity among caregiver-care-recipient dyads with moderate-to-severe MS, a comprehensive understanding of the shared physical activity experiences of these dyads would be beneficial. **Objective:** We explored shared experiences of caregiver-care-recipient dyads affected by moderate-to-severe MS about physical activity and directions for intervention. **Methods:** Six focus groups with 23 people with moderate-to-severe MS and 12 family caregivers were conducted. Data were analyzed using a constant comparative approach. **Results:** Three major themes emerged: 1) physical activity is a continuum; 2) cycle of disengagement; and 3) cycle of adjustment. The first theme captured the dyads understanding that physical activity falls along a continuum ranging from highly structured to unstructured activities. Cycle of disengagement captured the experiences of dyads engaging in little or no physical activity. These dyads perceived internal and external issues as drivers of the cycle of disengagement, while availability of supportive programs and services or people helped the dyads to break out of the cycle. When the cycle of disengagement was broken, the dyads described moving towards the cycle of adjustment, where they were able to learn skills and take action to incorporate physical activity into daily routines. **Conclusion:** This research highlights the need to adopt an integrative approach that acknowledges the caregiver-care-recipient dyad with moderate-to-severe MS as a focus for physical activity intervention.
3.4 Introduction

The progressive nature of multiple sclerosis (MS) and associated motor, cognitive and psychological symptoms mean that people with this condition may become increasingly disabled as the disease progresses\(^1\)\(^-\)\(^4\). Consequently, many people with MS, especially those individuals with moderate-to-severe disability (i.e., significant walking limitations that require support for gait PDDS 3–7 or EDSS ≥6) often need emotional, physical and instrumental support to manage associated life roles and maintain independence\(^5\)\(^,\)\(^6\). Providing this on-going support falls primarily on the family caregivers\(^7\)\(^,\)\(^8\) who may spend up to 10 hours per day for caregiving activities\(^9\)\(^,\)\(^10\). Together this evidence suggests that the impact of MS does not rest solely on the individual with disease, and that people with MS and their family caregivers often need to adapt to its presence as an interdependent caregiver-care-recipient dyad\(^11\). The definition of caregiver-care-recipient dyad adopted for this study is as follows: \textit{the reciprocal partnership of two or more persons who enact caring roles towards one another. This partnership may include the individual with a disease and a close friend or relative usually a spouse, adult child, sibling, unmarried partner, or parent}\(^12\)\(^,\)\(^13\).

Researchers have demonstrated that regular participation in physical activity has beneficial effects on all aspects of health and quality of life for all people including people with MS\(^14\)\(^-\)\(^16\). Yet recent estimates suggest that approximately 60% of people with MS are physically inactive (i.e., fail to meet public health guidelines of ≥30min/day of moderate-to-vigorous intensity activity) compared with 23% of the general population\(^1\). Furthermore, people with progressive subtypes of MS have lower physical activity levels compared to those who have a relapsing clinical course\(^17\), suggesting that a higher disability level is associated with physical inactivity\(^18\). With increasing caregiving responsibilities, family caregivers of people with moderate-to-severe MS-related disability may have limited time and opportunity to participate in physical activity\(^19\)\(^,\)\(^20\).
To date, physical activity promotion interventions in the MS literature have been individually oriented and focused primarily on individuals with mild-to-moderate MS-disability. However, the developmental-contextual model of coping with chronic disease suggests that the disease has an impact on both caregivers and care-recipients, and that dyads who engage in collaborative activities such as physical activity are more likely to experience better adjustment. Furthermore, research in other chronic disease contexts (e.g., cancer and dementia) has demonstrated that a dyadic approach to physical activity improves several health-related outcomes for the dyad including muscle strength, physical function and psychological health. Collectively, this work highlights the importance of targeting the dyad as an equal and interactive unit and suggests that physical activity promotion interventions that are mutually beneficial to the needs of people with MS and caregivers are warranted.

For researchers and clinicians to effectively promote physical activity among caregiver-care-recipient dyads with moderate-to-severe MS-related disability, a comprehensive understanding of the shared physical activity experiences of these dyads would be beneficial. Qualitative data are extremely valuable for providing insights to guide the development and implementation of appropriate interventions. However, the majority of qualitative studies on physical activity among people with MS do so from the perspective of those with mild disability, with little consideration given to the experiences of those with moderate-to-severe disability. Furthermore, no study has documented shared perspectives of caregiver-care-recipient dyads affected by MS about physical activity. In response, this qualitative study was undertaken to explore shared perceptions of caregiver-care-recipient dyads affected by moderate-to-severe MS-related disability about physical activity. A secondary objective was to identify directions for intervention among these groups in order to inform the development of an intervention that supports their joint engagement in physical activity. The main question that guided our research was: What are the shared perspectives of caregiver-care-recipient dyads with moderate-to-severe MS-related disability about physical activity?
3.5 Methods

3.5.1 Study design

We chose a qualitative, cross-sectional, descriptive study design to answer our research question. A focus group method was used, as it facilitates interactive discussion and exchange of ideas among participants. Such interactive focus group discussions are reported to provide deep insight into multiple views on health behaviors.

3.5.2 Setting and participant recruitment

Focus group participants were recruited from three communities with populations ranging from 39,000 to 474,800 located within a single Canadian province. Potential participants were informed of the study through: 1) a recruitment phone call to individuals who had participated in a previous study conducted by investigators in our research team and consented to being contacted for additional research projects; 2) newspaper advertisements; and 3) information flyers distributed through local MS clinics and MS Society chapters.

The principal investigator (PI) or a trained research assistant (RA) conducted a telephone screening using a pre-defined script developed for this study. During the phone screening, we asked the primary contact person (i.e. either the people with MS or caregiver) to provide contact details of a possible partner for the focus group. Once provided, the PI or RA made a separate phone call to the partner to screen for eligibility. Potential participants were eligible to take part in the study if they met the study’s eligibility criteria in table 3-A.
<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. ≥18 years old$^b$</td>
<td>1. Inability to tolerate a 90 minute discussion completed entirely in English$^a$</td>
</tr>
<tr>
<td>2. Self-reported diagnosis of MS$^b$</td>
<td>2. Unable or unwilling to attend one focus group and arrange own transportation$^a$</td>
</tr>
<tr>
<td>3. A PDDS score between 3 (moderate disability) and 6 (bilateral support required)$^b$</td>
<td></td>
</tr>
<tr>
<td>4. Providing at least 45 mins/day of support to a person with MS who has a PDDS score between 3 and 6$^c$</td>
<td></td>
</tr>
</tbody>
</table>

$^a$Criterion applies to both people with MS and family caregivers.

$^b$Criterion applies only to people with MS

$^c$Criterion applies only to family caregivers

PDDS, Patient Determined Disease Steps; MS, multiple sclerosis; Support – any emotional, physical or instrumental help offered to a person with MS.
3.5.3 Participants

A total of 97 individuals (58 people with MS and 39 caregivers) expressed interest in the study. Nineteen people with MS and 22 caregivers decided not to be screened after receiving more information about the study and what was involved. After completing the screening process, nine people with MS and five caregivers were deemed ineligible (due to disease severity or transportation difficulties). Another seven people with MS were eligible but chose not to participate because the group timing was inconvenient. Thirty-five eligible participants comprising of 23 people with moderate-to-severe MS-related disability and 12 caregivers returned a copy of the signed consent materials, and these individuals were enrolled in the study. A flow chart summarizing the recruitment and enrollment process is presented in figure 3-A.
Figure 3-A. Flow chart of study recruitment and enrollment process
3.5.4 Procedure

The focus groups were conducted between April and August 2015. Participants were assigned to groups based on practical reasons (i.e. timing and locations where participants were recruited) in order to make participation as straightforward as possible. Each focus group was composed of a mix of dyads and single individuals. These single individuals were people with MS whose caregivers did not attend the groups.

Before each focus group, participants completed self-reported questionnaires. The people with MS questionnaire captured information on the participants’ demographic (age, gender, marital status, education and current employment status) and clinical (type of MS, disease severity, years since diagnosis and impact of MS on walking) characteristics. The caregiver questionnaire captured information on the participants’ demographic characteristics (age, gender, marital status, relationship with people with MS, living arrangement, education and current employment status), and general caregiving information (years of providing support).

The PI facilitated all the focus groups, after receiving training from the senior author (MF). One additional member of the research team took notes, noted relevant non-verbal communication, assisted with logistics and oversaw the audio recording during the groups. A semi-structured discussion guide was used (provided in Appendix C). All the focus groups were digitally recorded and professionally transcribed.

3.5.5 Data Management and Analysis

Descriptive statistics were used to report the sample characteristics. Focus group data were analysed using a constant comparative approach\textsuperscript{40}. This approach was chosen to enable us to explore areas where the views of each partner converged or diverged in order to produce a shared understanding of the dyad experience of physical activity. The PI reviewed the transcripts against the digital recordings for accuracy
and replaced participants’ names with pseudonyms. The PI and RA independently coded the transcripts after multiple readings. The coding process began with making notes in the margins of the transcripts about the participants’ comments and what was interesting about them. The next step was to develop an initial list of codes by identifying concepts embedded within the data. During this process, the two researchers compared and discussed their codes until they reached consensus. When disagreements were encountered, the senior author provided guidance. Once all the initial codes were identified, the two researchers met with the senior author to review and refine the codes, as well as develop a coding framework.

The search for themes involved condensing the codes into descriptive categories that offered a conceptualization of the shared dyad experience of physical activity. Another meeting with the senior author was held, in which a hierarchy of overarching themes and subthemes was discussed. This process was complemented by the development of a thematic map, which provided an overall conceptualization of the patterns within the data and relationships between them. Different iterations of the thematic map were discussed and revised with the senior author to ensure the patterns and suggested relationships represented on the map were consistent with the agreed interpretation of the data. Exemplar quotations were extracted from the transcripts to provide a basis for understanding the themes and their unifying properties. The final themes, subthemes and definitions are provided in table 3-B. ATLAS.ti v7 software was used to facilitate data management and analysis.
Table 3-B. Themes, subthemes and definitions generated through the analysis process

<table>
<thead>
<tr>
<th>Themes and subthemes</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>physical activity is a continuum</td>
<td>Statements describing the range of structured and unstructured activities that people with MS and their family caregivers consider physical activity</td>
</tr>
<tr>
<td>Cycle of disengagement</td>
<td></td>
</tr>
<tr>
<td>Awareness of limitations</td>
<td>Statements that reflect personal awareness or insights about how issues with body structure and function limit the type of activities people with MS and their caregivers engage in or how to go about engaging in such activities.</td>
</tr>
<tr>
<td>Mourning loss</td>
<td>Statements where people with MS or family caregivers talk about missing or wishing they could still do activities they used to enjoy but can no longer do because of the presence of MS</td>
</tr>
<tr>
<td>Drivers of the cycle of disengagement</td>
<td>Statements about factors that make it difficult for people with MS and their family caregivers to break out of the cycle of disengagement</td>
</tr>
<tr>
<td>Inhibitors of the cycle of disengagement</td>
<td>Statements about factors that enable people with MS and their family caregivers to break out of the cycle of disengagement</td>
</tr>
<tr>
<td>Cycle of adjustment</td>
<td></td>
</tr>
<tr>
<td>Acceptance</td>
<td>Statements about coming to terms with the disease and accepting their new identity</td>
</tr>
<tr>
<td>Innovation and modification</td>
<td>Statements reflecting how people with MS continue to work independently or together with their family caregivers to find new options or modify previously enjoyed activities</td>
</tr>
</tbody>
</table>
3.5.6 Trustworthiness

The strategies recommended by Lincoln and Guba\textsuperscript{11} were used to ensure rigor. Dependability and confirmability were achieved by using an audit trail to connect the raw data and codes with themes and sub-themes. To enhance credibility, two researchers independently analyzed the data, discussed and compared findings, and consulted with the senior author in case of a disagreement. Each participant was mailed a summary of his/her individual focus group approximately two weeks after the group for member-checking. Each participant was asked to comment on the summaries if inaccuracies were detected. Participants were given the option to decline if they did not wish to be part of this procedure. Of the 35 participants, two declined to participate because of vacation plans, 21 responded and expressed no concerns with the summaries and 12 did not return the feedback form despite three follow-up attempts. Transferability was achieved by presenting sufficient contextual information and raw data in this paper to allow readers to evaluate the themes and to decide whether they can be applied to their own situations.

3.6 Results

3.6.1 Focus groups

In total, there were six focus groups and each group lasted an average of 93 minutes (SD=17.3; range=59–107 minutes).

3.6.2 Participants

Tables 3-C and 3-D display the demographic and clinical characteristics of the 35 participants. The sample was largely female (n=22). People with MS were aged between 37-71 years. Family caregivers were aged between 38-79 years.
Table 3–C. Characteristics of people with MS who participated in the focus groups

<table>
<thead>
<tr>
<th>People with MS (n=23)</th>
<th>Mean (SD)</th>
<th>Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (in years)</td>
<td>54.6(9.8)</td>
<td>37</td>
<td>71</td>
</tr>
<tr>
<td>PDDS</td>
<td>4.7(0.9)</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Disease duration (in years)</td>
<td>14.7(9)</td>
<td>1</td>
<td>31</td>
</tr>
<tr>
<td>MSWS–12 score</td>
<td>68.4(16.7)</td>
<td>38</td>
<td>98</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>7</td>
<td>30.4</td>
</tr>
<tr>
<td>Female</td>
<td>16</td>
<td>69.6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>MS type</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary progressive</td>
<td>5</td>
<td>21.7</td>
</tr>
<tr>
<td>Secondary progressive</td>
<td>2</td>
<td>8.7</td>
</tr>
<tr>
<td>Relapsing-remitting</td>
<td>11</td>
<td>47.8</td>
</tr>
<tr>
<td>Progressive relapsing</td>
<td>1</td>
<td>4.3</td>
</tr>
<tr>
<td>Unknown</td>
<td>4</td>
<td>17.4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment status</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unemployed (unable to work – disability)</td>
<td>17</td>
<td>73.9</td>
</tr>
<tr>
<td>Retired</td>
<td>6</td>
<td>26.1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marital status &amp; living arrangements</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married; living with spouse</td>
<td>10</td>
<td>43.5</td>
</tr>
<tr>
<td>Married; living with spouse and children</td>
<td>6</td>
<td>26.1</td>
</tr>
<tr>
<td>Single; living with parents</td>
<td>1</td>
<td>4.3</td>
</tr>
<tr>
<td>Single; living alone</td>
<td>1</td>
<td>4.3</td>
</tr>
<tr>
<td>Single; living with siblings</td>
<td>1</td>
<td>4.3</td>
</tr>
<tr>
<td>Separated; living alone</td>
<td>4</td>
<td>17.4</td>
</tr>
</tbody>
</table>

MS, multiple sclerosis; PDDS, Patient Determined Disease Steps; MSWS-12, Multiple Sclerosis Walking Scale (percentage score is presented. The higher the score, the greater the perceived impact MS is having on walking ability);
Table 3–D. Characteristics of family caregivers who took part in the focus groups

<table>
<thead>
<tr>
<th>Family caregivers (n= 12)</th>
<th>Mean (SD)</th>
<th>Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>57(13.8)</td>
<td>38</td>
<td>79</td>
</tr>
<tr>
<td>No. of years of providing assistance to person with MS</td>
<td>10.9(7)</td>
<td>2</td>
<td>20</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>6</td>
<td>50</td>
</tr>
<tr>
<td>Female</td>
<td>6</td>
<td>50</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level of education</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>High School</td>
<td>2</td>
<td>16.7</td>
</tr>
<tr>
<td>Technical/Trade school</td>
<td>1</td>
<td>8.3</td>
</tr>
<tr>
<td>College</td>
<td>7</td>
<td>58.3</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>2</td>
<td>16.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment status</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unemployed (unable to work – disability)</td>
<td>1</td>
<td>8.3</td>
</tr>
<tr>
<td>Retired</td>
<td>6</td>
<td>50</td>
</tr>
<tr>
<td>Homemaker; does not work outside the home</td>
<td>1</td>
<td>8.3</td>
</tr>
<tr>
<td>Part time (20-39 hrs/wk)</td>
<td>1</td>
<td>8.3</td>
</tr>
<tr>
<td>Full time (40 or more hrs/wk)</td>
<td>2</td>
<td>16.7</td>
</tr>
<tr>
<td>Not working (full time caregiver)</td>
<td>1</td>
<td>8.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Relationship to person with MS</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>8</td>
<td>66.7</td>
</tr>
<tr>
<td>Non-spouse</td>
<td>4</td>
<td>33.3</td>
</tr>
</tbody>
</table>

MS, multiple sclerosis
3.6.3 Themes

The experiences shared by the participants were captured in three related themes: “physical activity is a continuum”, “cycle of disengagement” and “cycle of adjustment” (see figure 3-B). Overall, the participants’ experiences of physical activity as a structured–unstructured continuum were consistent across the focus groups. The cycle of disengagement emerged from statements made by participants engaging in little or no physical activity. A combination of internal and external issues kept them locked in this cycle. These participants were able to engage in physical activity when they entered the cycle of adjustment, which occurred over a period of time. Availability and usage of adequate support systems helped them to break out of the cycle of disengagement and enter the cycle of adjustment. In the discussion that follows, the themes and subthemes are described with quotes that illuminate their meanings. At the beginning of each quote, a pseudonym is included with PwMS or CG used to denote a quote from a participant with MS or caregiver respectively.
Figure 3-B. Graphic depiction of study themes and the relationship between themes
3.6.3.1 Overarching theme: physical activity is a continuum

To orient the participants to the phenomenon of interest, we asked them to describe what physical activity meant to them. The main theme that emerged from the analysis of the focus groups was that physical activity falls along a continuum ranging from highly structured to unstructured activities. This theme was captured in the stories shared by both caregivers and care-recipients. We heard some dyads describe physical activity as any structured, planned and supervised activity that is performed within the boundaries of their physical (dis)abilities. These dyads shared examples of aerobic and strength training activities performed in exercise facilities, and under the supervision of professionals who have MS-specific knowledge. This conceptualization of physical activity was most apparent in stories shared by older dyads residing in larger communities with considerably more access to facilities and services such as subsidized gym memberships.

**Jason (PwMS) shared:**

> When I think of it [physical activity], I think of things like the adapted aquatic classes...what comes to mind are all the kinds of exercises I am able to do at the [name of facility] they also have a heated pool which is great...

Other dyads conceptualized physical activity in a fairly fluid and unstructured manner. These dyads described physical activity as any activity accumulated through leisure, everyday occupations and household activities (such as gardening), as well as actions taken while pursuing other goals (such as walking to work). This conceptualization of physical activity was mostly apparent in the stories shared by dyads affected by a more severe MS-related disability.

**Cody (CG) commented on accumulating physical activity through everyday household activities.**

> I think of gardening and cutting the grass. Even moving around the house as a caregiver. I find myself doing a lot more stairs, a little more in the garden, a little more outside. And a little more of just the day-to-day function around the house.
There were also examples of participants who conceptualized physical activity as a combination of structured and unstructured activities. This conceptualization was more apparent among people with MS, who discussed that at times (e.g., during a severe relapse), they had to “take a break from the routine” [going to the gym] and move from the structured towards the unstructured end of the continuum “while recovering from the relapse” (Pat, PwMS).

Despite the wide range of possible activities that were described in the continuum, some dyads reported participating in little or no physical activity. During the discussions, these same dyads expressed frustration and sadness at their current level of physical activity. People with MS talked about their daily physical and psychological struggles when trying to be active. Family caregivers, especially those providing care to more disabled individuals, discussed the need to become experts at providing adequate care and safety for their care-recipients during physical activity. In addition, these caregivers had to balance the caregiving activities while ensuring that they also were able to participate in and benefit from physical activity. Although these dyads expressed the desire to stay as active as possible, coping with these challenges and having to balance several dimensions of caregiving often resulted in them being unable to engage in physical activity. The experiences shared by these dyads were captured in the theme: cycle of disengagement.

3.6.3.2 Theme 2: Cycle of disengagement

This theme captured the reflections of the dyads on their inability to engage in adequate amounts of physical activity because of issues related to physical (dis)abilities, loss of independence and the unpredictable changes associated with dealing with MS. Although this theme was consistent across focus groups, it was expressed more clearly among dyads affected by a more severe MS-related disability. Within this theme, two sub-themes emerged during analysis: awareness of limitations and mourning loss.
Awareness of limitations: People with MS made statements reflecting personal awareness and insights about how bodily issues limit to some extent the type of activities they engage in, as well as how they go about engaging in those activities. Caregivers also described how the limitations experienced by their care-recipients restricted their own daily routines and participation of the entire family in physical activity. These same caregivers expressed the need to be constantly vigilant, monitoring the status of their care-recipient and using it as a determinant of daily activity choices.

Kim (PwMS) commented:

*I love to sew and I use a sewing machine. And my right leg is affected and it’s weak, and the coordination of it. And so I have to really put a lot more energy into sitting down and sewing. I’m going to have to learn to do it with my left foot so that it’s a little bit smoother. But that is another thing that it’s a leisure activity for me that I always enjoyed doing that’s just a little bit more difficult now because of MS*

Bob (CG) also commented:

*Just the speed of walking is an adjustment for me as well. I’m a fairly quick walker. When we’re together, we do not walk my speed, we walk hers and sometimes it’s aggravating because it’s just so stinking slow... But as I’m walking, I’m trying to gauge her to see how far she’s going to go and how the walking pattern is. If she’s stumbling as we’re walking out of the house, we’re not going far... I don’t know from which day to which day what it’s going to be. It’s just pay as you go...*

Mourning loss: people with MS described a sense of frustration when comparing previous and current abilities. Caregivers of these individuals also expressed sadness at losing the freedom and independence to engage in activities they previously enjoyed because of the added responsibilities of caregiving.

Tina (PwMS) commented:

*...To me when I think of it [physical activity], it’s such a loss because it’s more I think about what I used to do and what I would like to do...I used to dance and I used to teach fitness. I’m still grieving that loss of not being able to do that...*

Tim (CG) also shared this experience:
There are chores that need to be done around the house and things that she [PwMS] used to do before that I have now taken over and that’s offset some things that I used to enjoy. I used to go out for walks and hikes but I’m now sticking around a little bit more to do more around the house.

**Drivers of the cycle of disengagement**

As the dyads constructed their physical activity experiences, a set of drivers emerged as influencing the cycle of disengagement. These drivers constantly alerted participants to their poor functional status (e.g., reduced mobility) when attempting to be physically active. For some people with MS, external issues such as lack of supportive resources in the home and community, and negative feedback from others resulted in the decision not to participate in physical activity.

Nicole (PwMS) shared this experience about limitations with resources in the community:

> ...even in the community, an exercise class, they’re leading for like, you know, Joe Athlete. And it’s like hey, you know, don’t push people that can’t do it. I mean yes, push them a little bit but don’t make them feel degraded because they can’t keep up. So I felt...I think they made me feel that I was sort of like taking up someone else’s time who needed it more than I did. And so I just quit.

Eva (CG) reiterated this lack of supportive community resources:

> I don't see a lot of support here. I know even with Nancy [PwMS] now they have called and they’ve come over and they’ve talked to her. But to actually recommend places to go for physical activity or things to do, I haven’t seen that. And that’s in 17 years.

Cathy (PwMS) shared her experience of receiving negative feedback from others:

> My daughter told me to stop walking with them basically because it’s embarrassing when I fall. And she’s 6...I mean it’s like that because I walked with them this one particular day, and you know, I mis-stepped, just kind of fell over. But she turned around and looked at me and went, “Oh, mom Ah, it's embarrassing. I don't want you to walk us because it’s embarrassing when you fall”

For other participants like Tom (CG), internal issues such as the presence of comorbidity reduced physical activity participation.
... I was walking with Tracey [PwMS] but unfortunately I have arthritis in my hip now. And that comes with age and until I have that rectified, my walking is very limited.

**Breaking out of the cycle of disengagement**

As the dyads shared their experiences, it became apparent that the availability of supportive programs and services or people (healthcare providers and social networks) halted the cycle of disengagement. Accordingly, these resources acted by providing the dyads with the information and tools needed to support learning new skills and action taking with regards to engagement in physical activity. Once the cycle of disengagement was successfully halted, the dyads described moving towards the cycle of adjustment, where they were able to make changes in order to improve their level of engagement in physical activity. For some dyads, these changes included planning and making small adjustments to their daily life to ensure that they could participate in physical activity during the day. For instance, Bob (PwMS) reflected on how he now takes the stairs at work instead of the elevator and how he has been walking over to his co-workers’ desk rather than emailing them.

3.6.3.3 **Theme 3: Cycle of adjustment**

This theme was more apparent among dyads that were currently engaging in some physical activity and captured their reflections on the adjustments they had to make to incorporate physical activity into their daily routines. For most of the participants, the process of adjustment occurred over a long period of time, but as soon as they entered into this cycle, they reported needing less support to be able to maintain their physical activity. For these dyads, the adjustments involved redefining what physical activity meant to them and shifting their expectations on types of physical activity to engage in, as well as the mechanism of engagement. This theme was more common in stories shared by dyads who had been living with MS for many years and reflected in two sub-themes: i) acceptance and ii) innovation and modification.
Acceptance: The dyads talked at length about how having MS affected all aspects of their physical activity experience. They also shared the importance of accepting the reality of MS and adapting to the changes in their abilities to engage in physical activity, as well as the need to change the way they think about physical activity.

**Linda (PwMS) shared:**

...like I mean I’ll do as much as I can for the first 2 hours in the morning whether it’s cleaning the kitchen or whether it’s up and down the stairs with laundry. And that’s not every morning. But that’s my exercise. And then I’ll sit. And if I have to sit in my chair for 2 hours that’s okay. And so I just have learned, which was really difficult, just to accept that, so I don’t beat myself up about it or try and push myself too much. For me, physical activity – housework, vacuuming, like it takes me 3 days to vacuum my apartment.

Innovation and modification: Participants shared their experiences with finding other options or modifying existing types of activities so they could continue being active. Throughout this process, people with MS also reported working collaboratively with their family caregivers to problem-solve and identify ways to ensure continuous participation in physical activity.

**Leena (PwMS) described how she modified her physical activity:**

So for me, I’m doing things now modified. So I’m still enjoying that I can do those things. Like for aerobics, I can, with the fan blowing on me in my basement, with the treadmill. And I’m holding on because for me the big thing is balance or my legs giving out. So I can still get aerobics on the treadmill.

**Jen (PwMS) described working collaboratively with her husband to generate ideas for activities that they could try together:**

...I have cognitive difficulties too and I would get lost walking around shopping, which was very difficult to handle in the beginning. But it isn’t now. My husband helped me with that. I’ve got it, there's nothing I can do to change it. But I can work with it and with the support of my husband, coming up with other ideas about things we could do for physical activity and that worked amazing.
3.7 Discussion

While there is a growing body of evidence on the experiences of physical activity participation among people with MS, this literature has been individually oriented and focused primarily on people with mild-to-moderate MS-related disability. Our study is unique because it explores the dyadic perspective of people affected by moderate-to-severe MS-related disability about physical activity. This has not been done before. Given the literature suggesting the importance of treating the dyad as a unit, this work extends previous findings from populations with other chronic diseases such as cancer, dementia and cardiac disease to people affected by moderate-to-severe MS-disability.

Across the focus groups, the dyads were concordant in their description of physical activity as a structured–unstructured continuum. Several activities ranging from aerobic and resistance exercise training, to leisure activities and common everyday actions were included in the continuum. The widely varied options for possible physical activity has been previously reported in survey studies identifying common activities self-selected by individuals with less severe MS-related disability. Elsworth et al. observed that swimming, stretching and walking were the favorite activities selected by 27 people with MS who completed questionnaires as part of a larger focus group study. This evidence was extended by Weikert et al. who reported that the most common activities selected by 272 people with MS in a cross-sectional survey study were walking, weight training and bicycling.

Many participants in our study, especially those individuals with a more severe disability described engaging in activities in the unstructured end of the continuum. We speculate that this finding may have at least two explanations. First, in clinical practice and research, physical activity programs typically focus on exercise training, a subset of physical activity. Such programs have traditionally excluded people with higher disability levels. Thus, these individuals may feel that they have no support to engage in the more structured programs offered in exercise facilities. Second, people with MS were historically told...
not to engage in physical activity because of the belief that it can exacerbate the disease process and result in worsening of symptoms especially fatigue. It is possible that some participants in the study still hold some of these beliefs and do not participate in structured exercise to avoid fatigue. This possibility underscores the important role that health care professionals have to play in educating people with MS on physical activity and exercise as a therapeutic strategy for MS management, a finding supported by Learmonth and colleagues in their recent qualitative studies.

Some participants also discussed having to move from the structured to the unstructured end of the continuum to enable recovery after experiencing a severe relapse. This finding may be due to the perceived need to reduce the amount of physical activity participation in order to prevent worsening of the relapse and its symptomatic manifestations, although studies suggest that physical activity may be safe during a relapse. This study is the first to show that unstructured and structured physical activity are not mutually exclusive and that people with MS who have moderate-to-severe disability and their family caregivers can go back and forth along the continuum depending on individual circumstances. This finding suggests that a degree of choice and flexibility may be required when designing programs to support sustained physical activity participation among those affected by moderate-to-severe MS-related disability. The dyads were also concordant in their beliefs about the benefits of an active lifestyle, corroborating findings from previous individual-level qualitative research in MS.

The current study has highlighted a novel finding in relation to the influence of mutuality on the dyads’ participation in physical activity. Participants in this study described physical activity as an interpersonal experience, with caregivers and care-recipients sharing very similar struggles, frustrations and adjustments. Considering that people with MS and their family caregivers often react to the impact of the disease as one interdependent unit, this finding has implications for the design of future interventions. By designing an intervention around equal participation of the dyad in physical activity, researchers can simultaneously target the health and wellbeing of both caregiver and care-recipient with MS. This
approach may be practical in combating the threats that MS and caregiving place on the health of each partner and on them as an interdependent unit.

The dyads in this study also described how the complex interactions between issues related to physical (dis)abilities, loss of independence and freedom, changes associated with MS and negative feedback kept them in the cycle of disengagement and limited the types of physical activity they could engage in, as well as the mechanism of engagement. This finding highlights the multidimensional nature of physical activity behavior, and the crucial roles that physical and psychological factors play in its initiation and maintenance. In clinical practice, a coordinated multidisciplinary healthcare approach targeting the various dimensions of physical activity may help support sustained behavior change among individuals affected by moderate-to-severe MS-related disability and those who support them. The need for physical activity promotion through coordinated healthcare involving several health professionals has been echoed in previous studies among populations with neurological conditions including MS\textsuperscript{56,58-60}.

The dyads that were able to break out of the cycle of disengagement and enter the cycle of adjustment discussed the importance of supportive resources in the community and within their social networks. These supportive resources were described as the places, programs and services or people that participants turned to for tools and assistance to support their engagement in physical activity. Previous studies have repeatedly emphasized the beneficial effect of supportive resources on physical activity participation among people affected by chronic neurological conditions including MS\textsuperscript{62-65}, although studies have predominantly focused on the effect of supportive resources on the individual with the disease. In line with Cohen and colleagues\textsuperscript{66} and findings from our study, this body of evidence suggests that strategies such as exposure to peer mentoring support groups at regular intervals and providing advice on practical aspects of engaging in physical activity may enhance perceptions of social support for dyads affected by moderate-to-severe MS-related disability.
The dyads that were engaging in physical activity described how they had to accept the reality of MS and work collaboratively together to identify ways of successfully increasing levels of physical activity. The collaboration described by the dyads also manifested in terms of shared solutions to challenges and emotional support to cope with changing abilities and negative feedback. The positive influence of collaboration within dyads is consistent with previous research evaluating the efficacy of collaborative action on changing dyadic health behaviors\(^{67,69}\). For instance, Prestwich et al.\(^ {69}\) reported that participants who planned physical activity together with a friend or family member including when and where they would engage in these activities were more physically active than those who planned and acted in isolation. Other researchers have also demonstrated that collaborative adjustment between dyads provides greater perceived control and is associated with better physical health outcomes for the dyad\(^ {25,27,30,70}\).

Overall, these findings further emphasize the need for researchers and clinicians to situate the focus for intervention development on the needs of the dyad, a practice that has shown beneficial effects in populations with other chronic diseases such as cancer, dementia and cardiac disease\(^ {27,46-48}\).

### 3.7.1 Limitations

This study has some limitations that warrant consideration. First, our sample comprised majorly of middle-aged (40-59 years) and older adults aged \(\geq 60\) years. Given the literature suggesting that middle-aged and older adults with MS are less physically active than young adults affected by the disease\(^ {71}\), it is possible that our findings may have been influenced by age-related factors in addition to MS-disability. Future researchers may want to explore the differences in physical activity perspectives between young and older adults affected by moderate-to-severe MS-related disability. Second, we did not have objective information on the physical activity levels of all our participants. Future researchers may want to gather this information in next studies to provide additional depth of analysis.
Third, although we utilized many strategies to recruit both members of the dyad, recruiting family caregivers proved to be challenging. As a result, a “selection effect” may have occurred where the caregivers who participated in the focus groups may have been different from those who chose not to participate. Fourth, we combined caregivers and people with MS in the same groups rather than having separate groups. While this strategy allowed for an in-depth exploration of co-constructed experiences, it may have influenced what the partners felt they were able to say during the groups. For example, caregivers may have wanted to protect their care-recipients by not expressing certain views and vice versa. It is therefore possible that we may have been able to further tease out the nuances of the physical activity experience between caregivers and people with MS if we had conducted additional separate groups and this would be an interesting avenue for future research.

In addition, it is possible that the amount of caregiving time may influence perspectives on physical activity. Our study is limited by not having detailed information on caregiving time and tasks. Future researchers in these areas are encouraged to gather this additional information to look at this relationship. Finally, some of the challenges associated with focus groups include domineering or quiet members, the moderator’s inability to control the course of discussion and the unnatural setting in which the interviews are conducted. In this study, we attempted to manage these challenges through training of the facilitator, supervision by a senior investigator during each focus group, using a small group composition and ensuring that the focus groups occurred at a place and time of convenience for the participants.

3.8 Conclusion

This research has highlighted the need for both people with MS and caregivers to adapt to the impact of the disease on their lives and work together to find options to engage in physical activity. Given that participants described physical activity as a continuum of widely varied activities, interventions should not solely focus on promoting structured exercise, but also encourage everyday physical activity while
taking the needs of both caregivers and care-recipients into consideration. These findings highlight the vital importance of adopting an integrative approach that acknowledges the dyad as a focus for physical activity interventions, which is highly relevant given the rising burden of MS on society.
3.9 References


38. van Eyk H, Baum F. Evaluating Health System Change-Using Focus Groups and a Developing Discussion Paper to Compile the" Voices From the Field". *Qual Health Res.* 2003;13(2):281-286.


Chapter 4 Correlating physical activity patterns of people with moderate-to-severe multiple sclerosis disability and their caregivers

**Citation:** Fakolade, A., Finlayson, M., Parsons, T., & Latimer-Cheung, A. (In press). Correlating physical activity patterns of people with moderate-to-severe multiple sclerosis disability and their caregivers. *Physiotherapy Canada*. The accepted version of the manuscript is provided and is presented according to the journal’s guidelines.

**Funding information:** This work was also supported through a Doctoral Studentship Award from the Multiple Sclerosis Society of Canada, (Grant/Award Number: EGID 2022) to A. Fakolade.
4.1 The contribution of manuscript 2 to the dissertation

The second manuscript extends the findings of the first manuscript by objectively examining the notion of physical activity pattern interdependence within MS dyads. Although the findings do not support this notion, they do show low levels of physical activity in both partners in the dyad, and highlight the importance of identifying key community resources that can support these individuals to transition from an inactive lifestyle to a physically active one.

4.2 Sections included in and appendices associated with this chapter

Sections 4.3 to 4.8 and section 4.10 are included in the manuscript *Physiotherapy Canada (in press)*. Section 4.9 addresses comments/issues that were raised during the dissertation defense and provides additional information not published. The following appendices contain information associated with this chapter: Appendix A: Ethics approval; Appendix E: Letter of information and consent form; Appendix F: Instructions for wearing the accelerometer; Appendix G: Physical activity log
4.3 Abstract

**Purpose:** People with multiple sclerosis (MS) and their family caregivers often react to the impact of the disease as an interdependent dyad. The aim of this exploratory study was to examine the interdependence in the physical activity patterns of dyads affected by moderate-to-severe MS disability.

**Methods:** A total of 15 pairs of people with MS and their family caregivers wore accelerometers for 7 days. By collecting data simultaneously from both partners, we tested interdependence using the dyad as the unit of analysis.

**Results:** people with MS and caregivers averaged 4,091.3 (SD 2,726.3) and 6,160.2 (SD 1,653.0) steps per day, respectively. The mean number of minutes per day of sedentary, light, and moderate-to-vigorous activity for people with MS was 566.3 (SD 97.7), 167.4 (SD 94.0), and 7.6 (SD 12.4), respectively, and 551.9 (SD 92.4), 199.6 (SD 63.4), and 21.4 (SD 18.2), respectively, for caregivers. Interdependence between dyads for sedentary, light, moderate-to-vigorous activity, and step count was low and non-significant ($r = 0.20, 0.26, 0.13, \text{ and } -0.27, \text{ respectively; } p > 0.05$).

**Conclusions:** Although our findings do not support the interdependence of physical activity between caregiver-care-recipient MS dyads, they do show that both partners are not engaging in sufficient physical activity to achieve important health benefits. These findings are important because they indicate that the dyads are likely to benefit from interventions for changing physical activity behavior.

**Keywords:** physical activity, accelerometry, multiple sclerosis, caregivers
4.4 Introduction

Multiple sclerosis (MS) is the leading cause of non-traumatic neurological disability among young adults in Canada:¹ approximately 100,000 people are currently living with the disease,² and this number is expected to exceed 130,000 by 2031.³ Common features of MS, such as a decline in mobility and cognitive function, present challenges for managing associated life roles, and they negatively impact quality of life (QOL).⁴ Indeed, approximately 30% of people with MS need assistance from family members, usually spouses, to carry out their activities of daily living.⁵ While medical advances have improved life expectancy for people with MS,³ the rising prevalence of the disease means that an increasing number of caregivers are providing assistance to people with MS living at home.⁵

The resulting demand for assistance may affect caregivers’ own health. For example, caregivers of people with MS are more likely than the general population to report poor health-related QOL.⁷ Gupta and colleagues⁸ further demonstrated that, in comparison with caregivers of people with other chronic neurological conditions such as Alzheimer’s disease, MS caregivers experience more limitations on their activities, more emergency department visits, and more hospitalizations. Collectively, these issues can reflect caregiver burden, which has been described as the impact of the caregiving role on the wellbeing of the caregiver.⁹ Caregiver burden relates to the severity of symptoms and level of disability of the people with MS as well as the caregiver’s coping strategies and the quality of the relationship between the caregiver and care-recipient.¹⁰ Together, this research suggests that there is an interdependent, or dyadic, component to the caregiving role, and it points to the need to consider the health of both the people with MS and the caregiver as an interdependent unit rather than each in isolation.

One of the rehabilitation strategies used to manage some of the impact of MS on the health of each partner and on the caregiver-care-recipient dyad is increasing participation in physical activity. In the caregiving literature, studies have shown that regular participation in physical activity can help reduce
caregiver burden and improve the quality of sleep and QOL of caregivers of people with chronic health conditions such as Alzheimer’s disease and cancer.\textsuperscript{11,12} Beyond these benefits, caregivers who engage in regular physical activity are better able to deal with the physical and mental challenges associated with caregiving and thereby delay the institutionalization of their care-recipients.\textsuperscript{13} In the literature specific to people with MS, there is evidence demonstrating that the benefits of physical activity extend to managing the symptoms, slowing the progression of the disease, and improving the QOL of people with the disease.\textsuperscript{14,15} However, the majority of these studies have restricted the inclusion criteria to people with MS who are independently mobile, excluding individuals with higher disability levels (e.g., with significant walking limitations that require support for gait – Patient Determined Disease Step (PDSS) 3–7 or Expanded Disability Status Scale $\geq 6$).\textsuperscript{16,17} Furthermore, no studies have reported on the potential benefits of including both people with MS and their caregivers in the same physical activity intervention.

Although there is very limited research about dyadic physical activity behavior in the specific context of MS, examples of physical activity-related dyadic research are available in other populations.\textsuperscript{17-19} These studies indicate that dyads exhibit similar health-seeking or risky behaviors, and in particular, the characteristics of the dyad mutually interact to affect physical activity behavior. For example, in a cross-sectional study, Lopes et al.,\textsuperscript{20} reported positive correlation between best friend dyads for both sedentary behavior and moderate-to-vigorous physical activity (MVPA). Similar findings were reported in another study by Pettee et al.,\textsuperscript{21} involving healthy older adult spousal dyads. This evidence was extended by recent longitudinal studies showing that changes in both the absolute level and trajectories of physical activity in middle-aged and older adult dyads are concordant over time.\textsuperscript{22}

Although there is very limited research about dyadic physical activity behaviour in the specific context of MS, examples of physical activity-related dyadic research are available in other populations.\textsuperscript{18-20} These studies indicate that dyads exhibit similar health-seeking or risky behaviours, and, in particular, the characteristics of the dyad interact to affect physical activity behaviour. For example, in a cross-sectional
study, Lopes and colleagues\textsuperscript{21} reported a positive correlation between best-friend dyads for both sedentary behaviour and MVPA. Similar findings were reported in another study, by Pettee and colleagues,\textsuperscript{22} involving healthy, older-adult, spousal dyads. This evidence was extended by recent longitudinal studies showing that changes in both the absolute level and the trajectories of physical activity in middle-aged and older-adult dyads are concordant over time.\textsuperscript{23}

Current research is lacking, however, about the relationship between the physical activity behaviour of dyads affected by moderate-to-severe MS disability. An assessment of patterns of and interactions between dyads’ physical activity would be an important first step in determining the potential utility of dyadic physical activity interventions in MS. Therefore, the objective of this study was to examine the interdependence between dyadic physical activity patterns – for example, time spent in sedentary behaviour, light-intensity physical activity (LPA), and MVPA – in dyads affected by moderate-to-severe MS disability.

4.5 Methods

4.5.1 Design

We used an exploratory, descriptive observational study design.

4.5.2 Participants

We recruited participants from three communities located in a single Canadian province as part of a larger study investigating the development of a dyadic physical activity intervention in MS. The larger study involved a series of focus groups exploring the shared perspectives on physical activity of people with moderate-to-severe MS disability and their family caregivers. We asked dyads who participated in the focus groups to indicate on their consent forms whether they would be willing to participate in the current study. We also recruited dyads outside the groups by advertising in local MS clinics.
The first author (FA) or a trained research assistant screened potential participants for their eligibility to participate in our study. The eligibility criteria are described in Table 4-A. Our study was reviewed and approved by the research ethics board at our institution. All eligible participants provided written, informed consent.
<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. ≥18 years old†</td>
<td>1. Severe cognitive deficits (weighted score of &lt;12 on the short version Blessed Orientation Memory Concentration test)*</td>
</tr>
<tr>
<td>2. Self-reported diagnosis of MS†</td>
<td>2. Other medical conditions that may impair participant’s ability to engage in physical activity†</td>
</tr>
<tr>
<td>3. A PDDS score between 3 (moderate disability) and 6 (bilateral support required)‡</td>
<td></td>
</tr>
<tr>
<td>4. Providing at least 45mins/day of assistance to a person with MS who has a PDDS score between 3 and 6‡</td>
<td></td>
</tr>
</tbody>
</table>

*Applies to both people with MS and caregivers.
†Applies only to people with MS.
‡Applies only to family caregivers.

MS = multiple sclerosis; PDDS = Patient Determined Disease Steps.
4.5.3 Measures and procedures

The Actical accelerometer (Philips Respironics, Bend, OR) measures physical activity by registering the vibrations that occur during acceleration. The Actical produces a signal that is proportional to the magnitude and duration of the sensed acceleration. This signal is digitally converted into activity counts, which are then summed over a specified time-interval (epoch) length. The device contains an internal processor that provides step count data. The step count function detects vertical movement events, which are then translated into steps accumulated per minute. The Actical accelerometer has established reliability and validity in both the general population and people with MS.24,25

We measured participants’ height (cm) and weight (kg) using standard techniques at an in-person orientation meeting. All the participants were then asked to complete a self-report questionnaire, after which time they received an accelerometer and a physical activity logbook. The questionnaire for the people with MS captured background information on each participant’s demographic (age, sex, marital status, education, and current employment status) and clinical (type of MS, years since diagnosis, and perceived health status) characteristics. The family caregiver questionnaire captured background information on those participants’ demographic characteristics (age, sex, marital status, relationship to people with MS, education, and current employment status), general caregiving (type of support provided and years of support provided), and perceived health status.

We gave the participants verbal, written, and graphical instructions to wear the accelerometer on an elastic band over the non-dominant hip during all waking hours over a 7-day monitoring period. We defined waking hours as the moment participants got out of bed in the morning until the moment they got into bed in the evening. We instructed participants to remove the accelerometer only for sleeping or bathing and to maintain their routine daily activities during the 7-day period. Simultaneously, participants completed the logbook by recording the wear time and the type and duration of activities they performed.
Either the first author or the research assistant called the participants every other day to remind them to wear the accelerometer and to troubleshoot any issues that arose with the device. Participants were given a prepaid envelope in which to return the study materials after the 7-day period. Data were collected between April and October 2015.

### 4.5.4 Data processing and analysis

We downloaded raw data from the accelerometer using the manufacturer’s software. The downloaded data were then imported into the Personal Activity Location Measurement System (PALMS) for data processing. PALMS is a web-based software application that allows researchers to study the activity patterns of participants in free-living studies. Data were considered spurious if the accelerometer registered 20,000 or more counts per minute (cpm) or if ≥ 253 steps per minute (maximum number possible according to the manufacturer’s specifications). Accelerometer data were visually checked for compliance by comparing the accelerometer wear time against the participant-recorded wear time from the logbook. Non-wear time was defined as a period registering a zero count for at least 60 consecutive minutes. We computed wear time by subtracting non-wear time from 24 hours. A day was considered valid when the data presented with ≥ 10 hours of wear time with no periods of consecutive zeros exceeding 60 minutes. 

Dyads with at least three days of valid data were included in the analysis. Based on previous research, activity count cut-off points of < 100 cpm was classified as sedentary, 100 - 1,534 cpm was classified as LPA, 1535 – 3959 cpm was classified as moderate intensity physical activity, and ≥3960 cpm was classified as vigorous intensity physical activity. It is important to note that activity counts generated by the accelerometer have no real value until they are assigned a level of intensity. We calculated step counts and minutes as well as the percentage of wear time per day spent in sedentary behaviour, LPA, and MVPA (calculated to adjust for individual wear time).
By collecting data from both partners in the dyad, we used the dyad as the unit of analysis and examined dyadic physical activity interaction in the context of the actor–partner interdependence model (APIM) developed by Kenny.\textsuperscript{30} The APIM is a framework for collecting and analyzing dyadic data. It is based on the idea that, in an interacting relationship, an individual’s behaviour is affected not only by his or her own characteristics (actor effects) but also by the other person’s characteristics (partner effects) and the individual’s perceptions of that other person. The APIM also provides appropriate statistical techniques for measuring and testing these effects (e.g., hierarchical linear modeling).\textsuperscript{30}

Data analysis was performed using IBM SPSS Statistics for Windows, Version 24.0 (IBM Corporation, Armonk, NY). Data were first checked for normality by visually inspecting histograms and normal quantile-quantile plots, then confirmed using the Shapiro-Wilk test. Descriptive statistics (e.g., frequencies, means, and SDs) were obtained for the demographic and clinical variables. Before using the APIM, we tested its assumption of interdependence between distinguishable dyads using Pearson correlations; these correlations provide insight into the degree to which dyad partners’ scores on the accelerometer variables are significantly similar (or interdependent). Because our data violated this assumption, it was not advisable to continue using the APIM. Therefore, we had to treat our data as independent samples, using an independent sample t-test for normally distributed data and a Mann-Whitney U-test for data that did not follow a normal distribution. Statistical significance was set at $p \leq 0.05$. We calculated effect sizes (ES) to provide information about the magnitude of the difference between groups. There are various ways to calculate ES;\textsuperscript{31} because of our study design, we calculated it using Cohen’s d analysis (i.e., the difference between the mean scores for two groups divided by the pooled standard deviation). An ES > 0.8 is considered large; 0.5-0.8 is considered moderate; and 0.3 <0.5 is considered small.\textsuperscript{32}
4.6 Results

4.6.1 Participants’ characteristics

Of the 15 dyads enrolled in the study, one was excluded for having < 3 days of data. Therefore, 14 dyads were retained for the analysis (see the flow-through diagram presented as Figure 4-A). Participants’ characteristics are presented in Table 4-B. On average, people with MS were middle-aged females, with a mean age of 52.0 (SD 11.7) years, and with relapsing remitting MS (42.9%). Importantly, the median PDDS score was 5.0 (interquartile range [IQR] = 1.0), indicating disability severe enough to require the use of a cane or bilateral support for ambulation. The mean duration of the disease was 13.2 (SD 8.2) years. Caregivers were slightly older middle-aged, with a mean age of 54.1 (SD 13.5) years, and were male spouses (71.4%) who had been providing assistance to a people with MS for a mean of 10.8 (SD 6.8) years.
Figure 4-A. Flow chart of study recruitment process

Dyads recruited from the larger study n=7
Dyads recruited from the local MS clinics n=12

Declined screening after receiving more information n=2

Assessed for eligibility n=17

Declined to participate due to vacation plans n=2

Enrolled n=15

Data excluded due to <3 days of data n=1

Provided valid accelerometer data n=14
Table 4–B. Characteristics of the participants

<table>
<thead>
<tr>
<th>Variables</th>
<th>Response options</th>
<th>People with MS (n=14)</th>
<th>Caregivers (n=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Age, y</td>
<td></td>
<td>52.0(11.7)</td>
<td>54.1(13.5)</td>
</tr>
<tr>
<td>BMI, kg/m²</td>
<td></td>
<td>28.5(8.5)</td>
<td>27.6(4.9)</td>
</tr>
<tr>
<td>Disease duration, y</td>
<td></td>
<td>13.2(8.2)</td>
<td>__________</td>
</tr>
<tr>
<td>Caregiving duration, y</td>
<td></td>
<td>__________</td>
<td>10.8(6.8)</td>
</tr>
<tr>
<td>Median PDDS (IQR)</td>
<td></td>
<td>5.0(1.0)</td>
<td>__________</td>
</tr>
<tr>
<td>Sex</td>
<td>Male</td>
<td>4.0(28.6)</td>
<td>10.0(71.4)</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>10.0(71.4)</td>
<td>4.0(28.6)</td>
</tr>
<tr>
<td>Education</td>
<td>High school or less</td>
<td>5.0(35.7)</td>
<td>6.0(42.9)</td>
</tr>
<tr>
<td></td>
<td>College or other</td>
<td>7.0(50.0)</td>
<td>4.0(28.6)</td>
</tr>
<tr>
<td></td>
<td>University</td>
<td>2.0(14.3)</td>
<td>4.0(28.6)</td>
</tr>
<tr>
<td>Employment</td>
<td>Employed</td>
<td>0.0(0.0)</td>
<td>7.0(50.0)</td>
</tr>
<tr>
<td></td>
<td>Unemployed/stay at home</td>
<td>9.0(64.3)</td>
<td>2.0(14.3)</td>
</tr>
<tr>
<td></td>
<td>Retired</td>
<td>5.0(35.7)</td>
<td>5.0(35.7)</td>
</tr>
<tr>
<td>Marital status</td>
<td>Married/common law</td>
<td>12.0(85.7)</td>
<td>14.0(100.0)</td>
</tr>
<tr>
<td></td>
<td>Single/divorced/widowed</td>
<td>2.0(14.3)</td>
<td>0.0(0.0)</td>
</tr>
<tr>
<td>Type of MS*</td>
<td>Relapsing-remitting</td>
<td>6.0(42.9)</td>
<td>__________</td>
</tr>
<tr>
<td></td>
<td>Primary-progressive</td>
<td>3.0(21.4)</td>
<td>__________</td>
</tr>
<tr>
<td></td>
<td>Secondary-progressive</td>
<td>2.0(14.3)</td>
<td>__________</td>
</tr>
<tr>
<td>Providing assistance with</td>
<td>Mobility</td>
<td>__________</td>
<td>8.0(57.1)</td>
</tr>
<tr>
<td></td>
<td>Shower/bath</td>
<td>__________</td>
<td>2.0(14.3)</td>
</tr>
<tr>
<td></td>
<td>Dressing</td>
<td>__________</td>
<td>4.0(28.6)</td>
</tr>
<tr>
<td></td>
<td>Meal preparation</td>
<td>__________</td>
<td>12.0(85.7)</td>
</tr>
<tr>
<td></td>
<td>Transportation</td>
<td>__________</td>
<td>13.0(92.9)</td>
</tr>
<tr>
<td></td>
<td>Negotiating stairs</td>
<td>__________</td>
<td>10.0(71.4)</td>
</tr>
<tr>
<td></td>
<td>Getting in/out of bed</td>
<td>__________</td>
<td>3.0(21.4)</td>
</tr>
</tbody>
</table>

MS = multiple sclerosis, PDDS = Patient Determined Disease Steps, IQR = interquartile range; BMI = body mass index

*Three people with MS did not report the type of MS
4.6.2 Between-dyad correlations

The results of the Pearson correlations used to test the assumption of interdependence in each of the accelerometer variables indicate that the interdependence between dyads for sedentary behaviour, LPA, MVPA, and step count was low and non-significant \((r = 0.20, 0.26, 0.13, \text{and} -0.27, \text{respectively}; p > 0.05)\). As explained previously, it was not advisable to use the APIM any further because none of the correlations were statistically significant (i.e., the assumption of interdependence between distinguishable dyads was not supported by our data).

4.6.3 Patterns of physical activity

Table 4-C presents the means for step count and minutes per day of sedentary behaviour, LPA, and MVPA. It further shows the proportion of wear time spent in the three categories of physical activity, along with the proportion of participants who met the Canadian physical activity guidelines. Across the 7-day period, caregivers accumulated significantly more steps per day than their care-recipients \((t_{(26)} = -2.43, p = 0.02)\), with a large, positive ES \((d = 0.95)\). However, no significant differences were found between the groups in the average number of minutes spent in sedentary behaviour \((t_{(26)} = -0.40, p = 0.69, d = 0.16)\) or LPA \((t_{(26)} = -1.07, p = 0.29, d = 0.24)\). Comparing the average time spent in MVPA showed significant differences between the groups \((U = 27.50, p = 0.001)\), with a large, positive ES \((d = 0.92)\).

Between the people with MS and their caregivers, there were no statistically significant associations between accelerometer-derived (i.e., step count, time spent in sedentary behaviour, LPA, and MVPA) and sociodemographic variables (i.e., age, sex, marital status, education, and employment).

Overall, this sample of dyads spent approximately 9.3 hours per day (74.1% of wear time) in sedentary behaviour, 2.6 hours per day (24.1% of wear time) in LPA, and 13.3 minutes (1.9% of wear time) in MVPA. Only four (28.6%) of the caregivers were meeting Canadian physical activity guidelines for
MVPA (i.e., accumulating ≥ 150 minutes per week of MVPA). No person with MS accumulated up to 150 minutes per week of MVPA. Although the family caregivers took significantly more steps per day than the people with MS, neither group was meeting the 10,000 steps-per-day recommendations.
Table 4–C. Step Count, Time Spent in Physical Activity, and Percentage of Meeting Guidelines

<table>
<thead>
<tr>
<th>Accelerometer variable</th>
<th>Mean (SD) People with MS</th>
<th>Mean (SD) Caregivers</th>
<th>p-value</th>
<th>Effect size</th>
<th>CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step count</td>
<td>4091.36 (2726.29)</td>
<td>6160.22 (1653.01)</td>
<td>0.022</td>
<td>-0.95</td>
<td>-805.6-803.7</td>
</tr>
<tr>
<td>ST, m/d</td>
<td>566.37 (97.74)</td>
<td>551.94 (92.36)</td>
<td>0.69</td>
<td>0.16</td>
<td>-33.8-34.1</td>
</tr>
<tr>
<td>LPA, m/d</td>
<td>167.44 (94.00)</td>
<td>199.63 (63.39)</td>
<td>0.29</td>
<td>-0.42</td>
<td>-28.2-29.0</td>
</tr>
<tr>
<td>MVPA, m/d</td>
<td>7.63 (12.39)</td>
<td>21.46 (18.2)</td>
<td>&lt;0.001</td>
<td>0.92</td>
<td>-6.8-4.6</td>
</tr>
<tr>
<td>% of day spent in physical activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ST</td>
<td>76.41 (13.50)</td>
<td>71.85 (8.31)</td>
<td>0.28</td>
<td>0.43</td>
<td>-3.6-4.4</td>
</tr>
<tr>
<td>LPA</td>
<td>22.82 (12.60)</td>
<td>25.42 (7.70)</td>
<td>0.51</td>
<td>-0.26</td>
<td>-4.0-3.5</td>
</tr>
<tr>
<td>MVPA</td>
<td>1.03 (1.62)</td>
<td>2.85 (2.41)</td>
<td>&lt;0.001</td>
<td>-0.92</td>
<td>-1.6-0.2</td>
</tr>
</tbody>
</table>

Meeting MVPA guidelines

<table>
<thead>
<tr>
<th>Count (%)</th>
<th>Count (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0.0 (0.0)</td>
</tr>
<tr>
<td>No</td>
<td>14.0 (100.0)</td>
</tr>
</tbody>
</table>

ST = sedentary time; LPA = light physical activity; MVPA = moderate-to-vigorous physical activity;

MVPA guidelines = ≥ 150 minutes per week of MVPA.
4.7 Discussion

Our study extends the MS literature by exploring dyadic physical activity behaviour, an important first step in determining the potential utility of incorporating MS caregiver-care-recipient dyads into the same physical activity intervention. To our knowledge, no previous studies have reported the physical activity patterns of people with moderate-to-severe MS disability together with that of their family caregivers. Moreover, accelerometers were used to simultaneously measure physical activity in the dyads, which has never been done before.

Our findings provide new insights in this area by showing that the physical activity patterns of people with MS were not significantly correlated with that of their caregivers. This finding was unexpected, considering that previous studies have suggested that there is an inter-relationship between dyadic physical activity patterns. For instance, Anderssen and Wold found a moderate correlation between adolescent male dyads (r = 0.23) and adolescent female dyads (r = 0.31) for leisure-time physical activity. Recently, Lopes and colleagues showed that best-friend dyads (aged 13–18 years) were similar in moderate (ICC = 0.31) and vigorous (ICC = 0.32) physical activity and sitting time (ICC = 0.21). Other researchers have demonstrated a similarity in physical activity participation between older-adult, spousal dyads. For instance, in the study by Pettee and colleagues, an active husband was 2.97 (95% CI = 1.73, 5.10) times more likely to have an active wife. The authors also reported similar results when examining whether the wife’s physical activity status was an important determinant of the husband’s physical activity status (odds ratio = 2.48 [1.40–4.38]).

We speculate that the difference in findings between previous studies and this one has at least two possible explanations. First, none of the previous studies included dyads in which one partner was affected by a chronic neurodegenerative condition such as MS. It is possible that disease-specific factors such as the progression of the disability, the unpredictability of symptoms, and a complementary decline
in physical capacity\textsuperscript{34} may have a different effect on the pattern of engagement in physical activity in people with MS than on caregivers. For instance, caregivers may be more active because of their caregiving responsibilities; thus, it may be difficult for care-recipients to engage in the same manner and level of physical activity as their caregivers. Nevertheless, one study reported insufficient physical activity in both partners in the stroke caregiver-care-recipient dyad but did not measure the correlation in physical activity pattern.\textsuperscript{35}

Another possible explanation is that the previous studies typically measured physical activity using self-report questionnaires, which can introduce the bias of subjectivity and require participants to recall past events; both can result in inaccuracy in the measurements. The use of accelerometers in this study eliminates the bias associated with self-reporting.

Our results show that people with MS spent about 76\% of the wear time (566 minutes per day) in sedentary behaviour and engaged in LPA and MVPA for approximately 23\% (167 minutes per day) and 1\% (5 minutes per day) of wear time, respectively. This finding is consistent with previous studies of people with MS across the disability spectrum.\textsuperscript{36,37} For instance, Ezeugwu and colleagues\textsuperscript{36} showed a similar trend in people with MS with mobility disability (i.e., PDDS $\geq 3$), who were sedentary for about 533 minutes per day (65\% of the day) and engaged in LPA for approximately 280 minutes per day (34\%), while MVPA made up only 10 minutes (1\%) of their day. Recently, Klaren and colleagues\textsuperscript{37} showed that middle-aged adults (aged 40–59 years) with MS with mild disability (PDDS median= 2; IQR = 3) spent about 533 minutes per day in sedentary behaviour and engaged in LPA for about 288 minutes per day, while MVPA made up only 19 minutes of their day.

Little objective physical activity measurement in caregivers has been documented. However, older adult caregivers (mean age of 69 years) in the study by Marquez and colleagues\textsuperscript{13} spent about 260 minutes per day in LPA and 8 minutes per day in MVPA. The authors did not document the time spent in sedentary
behaviour. Recently, Schulz and colleagues\textsuperscript{38} measured physical activity across four time points after cardiac surgery in 28 patients (mean age of 70.7 years) and their caregivers (mean age of 69 years). Across the four time points, the authors reported that the caregivers spent 11–16 minutes per day in MVPA. A similar pattern was observed in our current study, although our caregivers spent 5–10 minutes per day in MVPA longer than the caregivers in the studies by Shulz and colleagues, and Marquez and colleagues. The minimal difference between these studies may be due to age-related factors because our caregivers were relatively younger (mean age of 54 years). Previous researchers have shown that physical activity declines with age in the general adult population.\textsuperscript{39}

Although the caregivers in our study engaged in more MVPA than the care-recipients, both groups were still far below the Canadian physical activity guidelines of $\geq 150$ minutes per week of MVPA for the general population. The significant proportion of the day spent in sedentary behaviour points to a risk of comorbidity in the dyads. Studies have shown that, regardless of physical activity status, sedentary behaviour is associated with a greater risk of diabetes, high blood pressure, increased blood lipids, and poorer long-term mortality outcomes.\textsuperscript{40} Therefore, physical activity interventions that target reducing sedentary behaviour and increasing MVPA may be particularly important for dyads affected by moderate-to-severe MS disability; this finding is supported by previous researchers.\textsuperscript{37}

Similar to previous research involving Canadian adults,\textsuperscript{41} participants in this study did not regularly meet the recommendations of 10,000 steps per day. Using the step count classification system for the general population proposed by Tudor-Locke and Bassett,\textsuperscript{42} the people with MS would be classified as sedentary, while their caregivers would be classified as low active. The number of steps accumulated by the people with MS in this study is consistent with previous research reporting an average step count of about 5,000 steps per day, with higher disability resulting in fewer steps.\textsuperscript{43} Although few studies have documented the step count of caregivers of people with chronic disease, our findings are consistent with research by
Zalewski and colleagues, who reported that caregivers of people with stroke accumulate a mean of 6,378 (SD 2,149) steps per day.

The significant difference in step count between the people with MS and their caregivers suggests that dyadic physical activity interventions may need to incorporate different strategies to enhance care-recipient and caregiver physical activity within the time constraints of caregiving responsibilities. Other researchers have suggested that shorter, more frequent bouts of activity may be more feasible for caregivers to accomplish given their time constraints. Educating MS dyads about the health benefits and methods of reallocating sedentary time to alternative activities (e.g., LPA and MVPA) may be an additional strategy for increasing physical activity participation in these groups; this idea is supported by previous studies. For instance, Hamer and colleagues reported that replacing sedentary time with an equal amount of MVPA was associated with favourable effects on the risk factors for cardiovascular disease. Other researchers have shown that replacing sedentary time with equivalent amounts of LPA is associated with an improvement in physical health and wellbeing among healthy middle-aged and older adults as well as individuals with chronic health conditions.

The health benefits of reallocating sedentary time to LPA suggests that targeting an increase in at least LPA in people with MS and their caregivers may be a practical and achievable way to induce change in physical activity behaviour rather than seeking to increase the levels of MVPA, which may be more challenging. This body of evidence, together with our current findings, underscores the need for physical activity interventions that are tailored to the population affected by moderate-to-severe MS disability.

**4.7.1 Limitations**

This study has limitations that warrant consideration. First, we used the same cut-off points for both people with MS and caregivers. Evidence suggests that people with MS expend more energy than healthy
controls despite similar activity counts. Therefore, the published cut-off points for interpreting the Actical outputs for healthy individuals may not be appropriate for people with MS. Although MS-specific activity cut-off points have been established for other accelerometer types (e.g., ActiGraph), no cut-off points have been published for the Actical among people with MS, and this may be an interesting avenue for future research. It is also possible that the step count classification system proposed by Tudor-Locke and Bassett for the general population may not be appropriate for the MS population because it may increase the risk of incorrectly classifying the physical activity level of people with MS.

Second, our participants were recruited from three small urban areas in a single Canadian province, and this design limits the generalizability of our findings. Moreover, it is possible that regional and/or geographical differences in the services available to support physical activity participation may influence physical activity patterns. Future researchers may wish to explore the differences in physical activity between caregiver-care-recipient dyads living in major metropolitan cities versus those who live in smaller areas.

A third limitation is that our sample consisted of middle-aged to older adults, and our results may not represent young people with moderate-to-severe MS disability. Finally, our small sample size made it difficult to test actor-partner influences on physical activity behaviour using the APIM. Future studies with larger samples may be interested in exploring specific caregiver-care-recipient characteristics that interact to affect dyadic physical activity behaviour.

4.8 Conclusion

Despite these limitations, the current study is the first, to our knowledge, to examine physical activity patterns in MS dyads. Although our data do not support the interdependence of physical activity between the dyads, our findings do show that both partners are not engaging in sufficient physical activity to
achieve important health benefits. These findings are important because they indicate that these dyads could benefit from interventions for changing physical activity behaviours.

**Key Messages**

**What is already known on this topic**

Physical activity has emerged as an alternative behavioural approach for managing the consequences of MS. However, the physical activity behaviour of caregiver-care-recipient dyads with moderate-to-severe disability has not yet been investigated.

**What this study adds**

This study shows that the physical activity patterns of people with MS were not significantly correlated with that of their caregivers. Nevertheless, both partners are far below the recommended level of physical activity needed to achieve important health benefits. Clinicians and researchers need to begin to adopt an integrative approach to focusing on caregiver-care-recipient dyads affected by moderate-to-severe MS for promoting physical activity interventions. Interventions may need to incorporate different strategies to enhance care-recipient and caregiver physical activity within the time constraints of caregiving responsibilities.
4.9 Comments raised during the dissertation defense and the candidate’s responses

**Comment 1:** Why was the Actical accelerometer chosen over other devices?

**Response 1:** We decided to use the Actical accelerometer for two reasons. First, because of budgetary constraints, Dr. Amy Latimer-Cheung (co-author of manuscript) offered an in-kind contribution of 10 Actical accelerometers, which were available from a previous project. In addition, the Actical accelerometer has established reliability and validity in both the general population and people with MS, which increased our confidence in using the device as an objective measure of physical activity in our sample.

**Comment 2:** What are some of the sources of error/variation? In other words, what are some of the limitations of using accelerometers?

**Response 2:** There are at least three possible limitations to consider when using accelerometers to capture physical activity participation. First, people with MS and their caregivers may engage in various non-weight bearing activities that may not be captured by the accelerometer due to technical limitations. Second, the published accelerometer cut-off points used to determine intensity of physical activity are walking-based, which may introduce bias towards other activities that do not involve walking e.g., upper limb movements and swimming. The final limitation is the inability to capture contextual information about how physical activity is accumulated (i.e., leisure, work, or transportation).

**Comment 3:** It appears that the participants completed a logbook that reported “wearing time, type and duration of activities”. Please explain why the synthesis of these data is not provided in this paper.

**Response 3:** To aid interpretation of the accelerometer output and assess how much of the data were exercise versus engagement in occupation, we provided the participants with a physical activity log. However, some participants failed to return the logs despite several follow-up attempts while others
completed them poorly with days missing and/or lacking any detail about what type of activities they were doing. Consequently, the physical activity log data were unreliable and not included or discussed in the manuscript. Thus, we are unable to report on how much exercise versus engagement in occupation was captured in the data.

**Comment 4:** Why not use a continuous measure or quartiles instead of the categorical (Yes/No) variable used to capture the proportion of participants accumulating the public health recommended 150 minutes per week of MVPA. Also, is the public health guideline a realistic guideline for your patient population?

**Response 4:** We chose not to use continuous measures or quartiles for two reasons. First, since continuous measures are influenced by extreme values in a sample and our data contained outliers with high minutes per week of MVPA, these values would need to be deleted for analysis purpose, further reducing our small sample. In addition, none of Q1, Q2 and Q3 split the sample at a point corresponding to 150 minutes per week of MVPA. Therefore, using quartiles would not provide a clear picture of whether or not participants were meeting the guidelines.

Although there are no specific guidelines for how much physical activity a person with moderate-to-severe MS disability should achieve, we speculate that striving for the 150 minutes a week of MVPA may not be realistic for such individuals. It is possible that these individuals may actually require less activity to achieve important health benefits. For instance, research on individuals with spinal cord injury who primarily use a wheelchair for mobility suggests that because of the extent of their deconditioning and inactivity, they achieve health benefits with even less activity than do able-bodied individuals. Indeed the aerobic component of the Canadian Physical Activity Guidelines for MS is in line by recommending that adults with mild to moderate MS disability should perform 30 minutes of MVPA at least 2 times a week to improve fitness, participation, and quality of life. However, these guidelines come from evidence obtained in people with MS who are at least somewhat ambulatory, that is, who have lower levels of disability. In fact, the exclusion criteria for the studies that support
these guidelines often eliminate those who have more severe MS disability. People with MS who have higher disability levels need similar guidelines to determine the minimum frequency, intensity, and duration of physical activity to improve health and decrease the risk of adverse health conditions. Therefore, further research is needed to provide evidence related to the amount and type of interventions that will enhance physical activity in people with MS who have moderate-to-severe disability in order to establish these guidelines.
4.10 References


Chapter 5 A concerns report survey of physical activity support needs of people with moderate-to-severe MS disability and their caregivers


The manuscript is presented according to the journal’s guidelines.

Funding information: This work was supported through a Doctoral Studentship Award from the Multiple Sclerosis Society of Canada, (Grant/Award Number: EGID 2022) to A. Fakolade.
5.1 The contribution of manuscript 3 to the dissertation

The third manuscript builds upon the first and second manuscripts by aiming to identify the most pressing needs for community resources that might support physical activity participation in the target groups and determinants of perceived need. The list of community resources was generated from the findings of the first manuscript (focus groups). During the focus groups, participants had generated a list of the ideal people, places, programs and services that they would turn to for tools to help them initiate and/or maintain a physically active lifestyle. The survey allowed us to explore the importance of and satisfaction with these resources in a larger sample. The exploration of determinants of perceived need also extends the findings from manuscript one by identifying those individuals who are more likely to benefit from future development of resources to address the identified needs. Finally, given that the second manuscript showed that neither people with MS nor their caregivers were meeting recommended levels of physical activity participation, manuscript three also aimed to identify factors considered as barriers to solo– and co– participation in physical activity. Overall, manuscript three contributes to the overarching goal of the dissertation by identifying the need for a multiple level resource that incorporates affordable options for exercising together and innovative methods of information outreach to both people with MS and their caregivers.

5.2 Appendices associated with this chapter

The following appendices contain information associated with this chapter. The following appendices contain information associated with this chapter: Appendix H: Ethics approval; Appendix I: Physical activity concerns report survey for people with MS; Appendix J: Physical activity concerns report survey for family caregivers.
5.3 Abstract

**Purpose:** To identify the most pressing needs for community resources to support physical activity participation, determinants of perceived need, and barriers to sole- versus co- participation in physical activity for people with multiple sclerosis who have moderate-to-severe disability and their family caregivers.

**Methods:** A cross-sectional survey study guided by the Concerns Report Methodology.

**Results:** Three need items were prioritized by both groups: 1) information about available resources to support physical activity participation; 2) programs that support joint participation of people with multiple sclerosis and family caregivers in physical activity; and 3) programs that have affordable total cost of participation. A broad range of factors (i.e., education, living situation, type of community, marital status, and income, as well as comorbidity status) was significantly associated with one or more of these need items. Although there was variability in the perception of barriers between people with multiple sclerosis and their caregivers, several modifiable impairment-related, personal and logistical factors were identified by both groups.

**Conclusion:** The results suggest that a multilevel resource that incorporates affordable options for exercising together and innovative methods of outreach is needed. Factors associated with perceived need may guide efforts to target individuals with greater support needs.

**Keywords:** Community resources, physical activity, multiple sclerosis, caregiver care-recipient dyads, moderate-to-severe disability.
5.4 Introduction

Multiple sclerosis (MS) is a chronic progressive neurological condition with a prevalence of 291 per 100,000 people in Canada. The prevalence rate is projected to rise to 430 cases per 100,000 people, corresponding to over 130,000 Canadians living with MS by 2031. Many people with MS, especially those individuals with moderate-to-severe disability, often cope with disease-related stressors including decline in functional status (e.g., poor mobility) and physiologic deconditioning. As a result, these individuals may require assistance to manage associated life roles in the home and community. The task of providing this ongoing assistance falls primarily on family caregivers. MS caregivers provide about 80% of the care people with MS need, and may spend ≥10 hours/day in various caregiving activities.

Although there are positive aspects of providing care to people with MS, caregivers also experience significant stress due to the physical and emotional dependency that develops among their care-recipients as the disease progresses and disability accumulates. As a result, people with MS and their caregivers often need to work collaboratively to identify strategies to manage and cope with disease- and caregiving-related stressors.

The Developmental Contextual Coping Model provides a theoretical framework for understanding dyadic coping in chronic diseases such as MS. The model describes four strategies that may be used to manage disease- and caregiving- related stressors. These strategies include: 1) uninvolved coping, where each partner is coping alone with their individual stressors; 2) supportive coping, which describes the provision of physical, instrumental or emotional support from one partner to the other person; 3) collaborative coping, which extends beyond the provision of social support to a situation whereby both partners actively negotiate aspects of their shared experience and take equal responsibility for engaging in practical coping strategies (e.g., joint problem solving and goal setting for physical activity); and 4) control strategies where one partner, usually the caregiver, underestimates the abilities of and dominates the actions of the other partner by taking charge and telling the other person what to do.
According to the Developmental Contextual Coping Model, dyads who jointly appraise the disease as a shared disease, pull resources together and engage in collaborative coping strategies are better able to confront and overcome the challenges of living with and managing chronic diseases. Thus, the model emphasizes the importance of considering the health of the person with a chronic disease and his/her caregiver as an interdependent unit rather than each in isolation. Research investigating this model has also shown that collaborative coping strategies contribute to beneficial health outcomes including reduction in self-reported heart failure symptoms, and improvement in metabolic control and quality of life among dyads affected by various chronic diseases. In particular, joint participation in physical activity may improve exercise adherence, muscle strength, physical function and psychological health for both partners, as well as caregiver coping skills.

Despite models such as the Developmental-Contextual Coping Model, few researchers have included people with MS who have moderate-to-severe disability and their caregivers as co-participants in studies. Current literature is also lacking as to what factors affect sole-participation (i.e., people with MS or caregiver alone) versus co-participation (i.e., people with MS and caregivers together) in physical activity. These issues limit our ability to identify strategies to enhance dyadic participation in physical activity in the presence of unique caregiver and care-recipient barriers. In addition, service providers and individuals working in public health systems need to be aware of the dyads’ perceived need for community resources that might support their participation in physical activity, as well as the determinants of perceived need. Such knowledge is an important prerequisite to developing the necessary types and scopes of resources for reducing unmet needs. Identifying determinants of perceived need may also provide guidance for targeting efforts to ensure optimum utilization of such resources.

Research that attempts to examine perceived need is guided by a number of conceptual models, the most common of which is the Andersen-Newman model. Originally developed to predict health service utilization, it has now become an extensively used model for needs assessment and analysis of factors that
can influence perceived need. In the original model, Andersen and Newman describe individual and societal determinants of health service utilization. Within the individual factors, three types of variables are considered: predisposing characteristics, enabling factors and health need factors.

Predisposing characteristics (e.g., age, sex) are hypothesized to increase an individual’s inclination or tendency to use services. Enabling factors (e.g. income and living situation) impede or facilitate individuals to use service. Health need factors (e.g., overall health status and disease conditions) trigger the use of services. The Andersen-Newman model is a flexible and robust conceptual framework that allows the selection of variables and suitable methods related to the researcher’s area of interest or specific hypothesis. The model also provides a suitable framework when exploratory research is needed due to dearth of previous research in an area, as in this study. Consequently, the individual determinants component of the Andersen-Newman model has been used in diverse disciplines including gerontology, mental health, oncology, and physiotherapy.

This study incorporated the theoretical framework of the Developmental-Contextual Coping Model and the conceptual model of Andersen-Newman to examine the most pressing needs for community resources to support physical activity participation in people with moderate-to-severe MS disability and their caregivers. We were also interested in identifying determinants of perceived need and the barriers to sole- versus co-participation in physical activity in these groups. For the purposes of this study, we defined community resources as follows: the people, places, programs and services that members of a given community (i.e., people with MS and their caregivers) can turn to for tools to help them initiate and/or maintain a physically active lifestyle.
We focused on three research questions:

1. What are the most pressing needs for community resources to support physical activity participation in people with moderate-to-severe MS disability and their caregivers?
2. What are the predisposing characteristics, enabling and health need factors that are associated with the most pressing needs?
3. What are the barriers to sole- versus co-participation in physical activity for people with moderate-to-severe MS disability and their caregivers?

5.5 Methods

5.5.1 Study design

A cross-sectional survey study using the Concerns Report Methodology was conducted. The Concerns Report Method is a systematic participatory approach to needs assessment that includes agenda setting, capacity building and empowerment for change among individuals who share a common issue. The Concerns Report Method is particularly useful in getting the community members and needs assessment team to prioritize the needs and concerns within a community. The prioritized list can then inform the development or planning of appropriate resources. There are five basic phases of the Concerns Report Method, described in table 5-A. It is important to note that phases one through three identify and prioritize needs and concerns, while phases four and five focus on planning actions and solutions, which can take several years. This study focuses on the survey development (phase 2) and dissemination (phase 3) of the Concerns Report Methodolog. The findings from the focus groups (phase 1) have been published previously.
Table 5–A. The phases of the Concerns Report Methodology

<table>
<thead>
<tr>
<th>Phase</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Focus Groups</td>
<td>Focus groups are conducted with representatives of the population being studied to identify community values and general needs.</td>
</tr>
<tr>
<td>2. Development of a structured survey</td>
<td>A working group of key informants is assembled to actively contribute to the development of a structured survey using findings from the focus groups. Each item in the Concerns Report survey has an importance dimension (scored on a scale ranging from 1 ‘not important’ to 4 ‘very important’) and a satisfaction dimension (scored on a scale ranging from 1 ‘not satisfied’ to 4 ‘very satisfied’);</td>
</tr>
<tr>
<td>3. Survey dissemination and analysis</td>
<td>The Concerns Report survey is disseminated as broadly as possible to allow as many members of the community to participate. Analyzing the survey involves the calculation of a Need Index for each item. The Need Index is calculated as follows: The proportion of respondents who state that an item is very important is calculated; The proportion of respondents who state that they are very satisfied with the item is calculated; and Need Index = proportion very important – proportion very satisfied. The Need Index allows the needs assessment team to be able to identify community needs and concerns in order of priority. Responses are classified based on the Need Index into: 1) concerns and needs - survey items that a majority of respondents rate as high in importance and low in satisfaction; and 2) strengths - survey items that a majority of respondents rate high in importance and in satisfaction.</td>
</tr>
<tr>
<td>4. Public meetings and action committees</td>
<td>A “public meeting” is convened to discuss the results of the survey with community members and generate ideas for further action to address needs and concerns. An action committee is set up to plan and implement programs or services that address the needs of the community</td>
</tr>
<tr>
<td>5. Monitoring and feedback</td>
<td>Monitoring of the committees and dissemination of the final report throughout the community</td>
</tr>
</tbody>
</table>
5.5.2 Survey development

Two separate surveys were developed based on the findings from the focus group study (phase 1) (7) – one for people with MS and the other for caregivers. The process of developing the surveys was iterative and involved four researchers (AF, ALC, TP and MF), three people with MS and two caregivers (hereafter referred to as the team). The people with MS and caregivers were identified from the focus group participants.

The survey development process began with the lead researcher (AF) generating a preliminary list of survey items from concepts embedded within the focus group data. Then, she sent draft copies of the surveys via email to the team for review and feedback. The next step involved a face-to-face meeting, during which the team discussed comments and feedback and identified additional items to be included in the surveys. The team agreed that the surveys should include potential factors that might have relevance as barriers to both sole-participation and co-participation in physical activity. It was also agreed that whenever possible, questions that had proven reliability and validity from previous self-reported measures should be included in the respective surveys (e.g., short-form International Physical Activity Questionnaire 27; Coping with MS Caregiving Inventory 28). Subsequently, the lead researcher revised the surveys and included the additional questions that resulted from the meeting discussion. Finally, an updated version of the surveys was sent to the team via email for final comments. No additional changes to the content of the surveys were suggested at this time.

To evaluate the length and logic, as well as minimize the risk of confusing questions in the surveys, a pilot involving two people with MS and two caregivers was conducted from May 5-12, 2016. Individuals who participated in the pilot were different from the team. During this step, we determined that median completion time for the surveys was approximately 25 minutes. The pilot data were not included in the final analysis.
5.5.3 Survey content

Each of the final surveys (see Appendices I and J) consisted of five sections with questions related to the following:

5.5.3.1 Current physical activity

The first section gathered information on routine moderate-to-vigorous physical activity over the previous one-week using questions from the short-form International Physical Activity Questionnaire. An additional question asked the participants to list the activities in which they routinely engaged over the previous one-week. For the purposes of this study, we described moderate intensity physical activity as follows: *any planned or incidental activity that causes participants to sweat a little and to breathe harder than normal or during which they could talk but not sing.* Vigorous intensity physical activity was described as follows: *any planned or incidental activity that causes participants to sweat and be out of breath or during which they could not say more than a few words without pausing for a breath.* The short-form International Physical Activity Questionnaire was scored according to guidelines.

5.5.3.2 Community resources

The items in this section asked respondents to rate the importance of and satisfaction with 13 community resources that might support physical activity participation on a scale of 1 (completely unimportant/completely unsatisfied) to 5 (very important/very satisfied). The list of community resources was derived from the focus group study (phase 1 of Concerns Report Methodology). These items were considered the “Community Concerns” domain of the surveys, and were used to generate the Need Index using the previously described formula (see table 1). The items that over 50% of the respondents rated as high in importance and low in satisfaction (i.e., needs and concerns) are the focus of this article. There are
no published cut-off points for decisions based on the Need Index. We chose >50 because it indicates that 50% or more of the participants identified the item as a need.

5.5.3.3 Barriers to physical activity

The third section gathered information on barriers to sole- versus co- participation in physical activity. No existing measures of barriers to sole- versus co-participation in physical activity were available, so the team selected and adapted items from instruments used in previous studies involving people with chronic health conditions including MS $^{31-33}$ and the general physical activity literature $^{34}$. Participants were asked to rate the barriers on a scale of 1 (very small barrier) to 5 (very big barrier), as described by Vasudevan and colleagues. $^{31}$ Table 2 provides an example of a barrier (lack of motivation to initiate and maintain participation in physical activity) selected from the work of Vasudevan and colleagues $^{31}$ and how it was framed in the survey for people with MS.
Table 5–B. Example of a survey from a previous study and how it was framed in the survey for people with MS

<table>
<thead>
<tr>
<th>Original Question</th>
<th>How it was framed in our study</th>
</tr>
</thead>
<tbody>
<tr>
<td>In general, when you encounter lack of motivation to be physically active, how much of a barrier was it on a scale from one to five, with one being very small and five being very big</td>
<td>Thinking about sole-participation (i.e. you alone) and co-participation (i.e. with a supportive close friend or family member) in physical activity, please indicate how much of a barrier each of the following items is to you personally when you participate in physical activity alone versus with a supportive close friend or family member</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item</th>
<th>Sole-participation</th>
<th>Co-participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of motivation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>○ very small barrier</td>
<td>○ very small barrier</td>
<td></td>
</tr>
<tr>
<td>○ small barrier</td>
<td>○ small barrier</td>
<td></td>
</tr>
<tr>
<td>○ neutral</td>
<td>○ neutral</td>
<td></td>
</tr>
<tr>
<td>○ big barrier</td>
<td>○ big barrier</td>
<td></td>
</tr>
<tr>
<td>○ very big barrier</td>
<td>○ very big barrier</td>
<td></td>
</tr>
</tbody>
</table>
5.5.3.4 General Health

The fourth section gathered information on general health. For people with MS, the questions inquired about type of MS, diagnosis year, current mobility status, use of an assistive aid, self-rated health and comorbidity status. A single measure was used to measure self-rated health as excellent, very good, good, fair or poor. To gather information on comorbidity status, participants were asked, based on the work of Marrie and colleagues if they had been diagnosed (yes/no) with hypertension, hyperlipidemia, chronic lung disease, depression and anxiety. For caregivers, we gathered information about self-rated health, comorbidity status and caregiver coping skills. The coping skills were measured using the Coping with MS Caregiving Inventory.

5.5.3.5 Socio-demographic information

The final section gathered information on basic socio-demographic characteristics (age, sex, marital status, living situation, education, and employment status, type of community and income status). Type of community was categorized based on definitions from Statistics Canada 2011 Census Dictionary. Income status was categorized based on the Statistics Canada 2013 Canadian Income Survey. For the caregivers only, we added additional questions about their relationship to the person with MS, as well as the nature of assistance being provided and the number of years of providing assistance.

5.5.4 Survey dissemination

The surveys were disseminated using Fluidsurvey software, an online survey system. We chose to use online surveys because of the high use of the internet by people with MS and their caregivers, as previously documented, as well as the ease of access, simplicity and minimal budgetary and time commitment associated with this method of dissemination.
5.5.5 Participant recruitment

To limit the possibility of losing interested individuals and for ease of participation, we recruited in two distinct streams – one stream for people with MS and the other for caregivers. This method ensured that, if desired, people with MS could participate independent of their caregivers and vice-versa. We recruited potential participants by sending personal e-mails containing a link to the appropriate surveys (i.e., for people with MS; for caregivers) to individuals who had participated in previous studies conducted by our research team and who had consented to being contacted for additional MS research projects. In addition, each MS Society chapter across Canada was contacted by email to request that a link to each of the surveys be distributed to their members. Information flyers were also distributed through the MS Society of Canada Research Portal. Finally, snowball sampling was used to identify participants. A survey item at the end of each survey asked participants to forward a link to either the person with MS or caregiver depending on the primary respondent. Given these recruitment strategies, the total number of people with MS and caregivers who received the survey link was not known; therefore, we were unable to determine a response rate.

5.5.6 Eligibility criteria

Given our recruitment strategies, it was advisable to include screening questions for eligibility as part of the surveys. Therefore, when potential respondents activated the survey link, they were guided to the survey website where they were presented with detailed information about the purpose of the study. Individuals were then invited, via the website, to consent and undergo an online screening process where they had to confirm that they met the inclusion criteria for the study. The survey was automatically terminated if they did not meet the criteria outlined in table 5-C. The Research Ethics Board at the authors’ institution approved all study procedures.
Table 5–C. Eligibility criteria for people with MS and family caregivers

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. ≥18 years old(^a)</td>
<td>1. Inability to complete the survey in English(^a)</td>
</tr>
<tr>
<td>2. Diagnosis of MS(^b)</td>
<td></td>
</tr>
<tr>
<td>3. A score between 3 (moderate disability) and 6 (bilateral support required) on the Patient Determined Disease Steps(^b)</td>
<td></td>
</tr>
<tr>
<td>4. Providing at least 45mins/day of support to a person with MS who has a score between 3 and 6 on the Patient Determined Disease Steps(^c)</td>
<td></td>
</tr>
</tbody>
</table>

\(^a\)Applies to both people with MS and caregivers
\(^b\)Applies only to people with MS
\(^c\)Applies only to caregivers

MS – multiple sclerosis
Support – any emotional, physical or instrumental help offered to a person with MS
5.5.7 Participants

A total of 197 individuals (122 people with MS and 75 caregivers) consented to the survey. However, 30 people with MS and 24 caregivers decided not to be screened and discontinued the survey after providing consent. After completing the screening process, eight people with MS and one caregiver were deemed ineligible (due to disease severity or age). Another five people with MS and four caregivers were eligible but chose to discontinue the survey after completing only the screening process (i.e., they did not proceed to answering any of the survey questions). Therefore, the final sample consisted of 124 respondents (78 people with MS and 46 caregivers). A flowchart of the study recruitment process is presented in figure 5-A.
Figure 5-A. Flowchart of study recruitment process
5.5.8 Data analysis

The data were downloaded from Fluidsurvey and imported into IBM SPSS Statistics for Windows, version 24 (IBM Corp, Armonk, NY) for analysis. Missing Value Analysis was performed to examine the pattern of missing data. Participants were excluded from the analysis if they failed to complete 90% or more of the survey items. List-wise deletion was used for item non-response.

5.5.8.1 Analysis for Aim #1 – What are the most pressing needs for community resources to support physical activity participation among people with moderate-to-severe MS disability and their caregivers?

We calculated the Need Index for each of the 13 items in the “Community Concerns” domain of the surveys as previously described (see table 5-A). To evaluate the extent to which the perceived needs of people with MS were different from those of the caregivers, a Need Index was generated separately for each group and compared. Then, based on a score of >50 on the Need Index, we identified community resources that were prioritized by both people with MS and caregivers.

5.5.8.2 Analysis for Aim #2 – What are the predisposing characteristics, enabling and health need factors associated with each of the pressing needs?

To prepare for the analysis process, an outcome variable was derived for each of the 13 items and labeled Need Gap (i.e., Need Gap1- Need Gap13): The variables were each dichotomized into Need Gap-reported and Need Gap-not reported. We coded Need Gap-reported, as all the respondents who indicated that the community resource was very important, but the resources they were currently receiving were unsatisfactory. For a conservative approach, all other responses (i.e., important and satisfied, unimportant and satisfied, or unimportant and unsatisfied) were coded as Need Gap-not reported. Once the outcome variable was derived, analysis proceeded by first examining all of the variables of interest using summary statistics (i.e., frequencies, means, standard deviations) and then comparing
descriptive characteristics across the groups of interest (i.e., Need Gap-reported versus Need Gap-not reported). All bivariate comparisons were assessed using Pearson chi-square or t tests, depending on the nature of the variable. The Andersen-Newman model guided the selection of covariates for the final logistic regression model. We selected covariates in each category (i.e., predisposing, enabling and health need) to ensure a comprehensive examination of the factors associated with perceived need.

The predisposing factors examined in this study were sex, age and education (<college, ≥college). The enabling factors considered in these analyses were marital status (single, married), living situation (live alone, live with someone else), employment (currently working, not working), personal annual income and type of community. Because of a small sample size for some response options, personal annual income was collapsed to create a dichotomous variable (<$50,000CAD and ≥$50,000CAD). Type of community was also collapsed to create a dichotomized variable (medium/large urban and small town/rural). The health need factors examined in these analyses were health status (poor-to-fair, good-to-excellent), comorbidity status, and meeting the Canadian Physical Activity Guidelines for the general population. Because of a small sample size for some response options, comorbidity status was collapsed to create a dichotomous variable (no comorbid conditions and ≥1 comorbid condition). Participants who reported spending >150min/week in physical activity, based on scores on the short-form International Physical Activity Questionnaire, were classified as meeting the Canadian Physical Activity Guidelines, while those with <150min/day did not meet the guidelines.

Multicollinearity among the variables was assessed using the Variance Inflation Factor, while model fit was assessed by the Hosmer and Lemeshow goodness-of-fit test. Two sets of analyses were carried out to examine factors associated with perceived need. The first set of analyses combined both people with MS and their caregivers together in the model, while the second set of analyses was done on each group separately.
5.5.8.3 Analysis for Aim #3 – What are the barriers to sole-versus co-participation in physical activity among people with moderate-to-severe MS disability and their caregivers?

Because of a small sample size for some response options, the responses were collapsed and dichotomized (small barrier and big barrier). For ease of presentation, we focused on only items reported as big barriers and conducted descriptive analysis (frequency distributions (n [%])) to determine the most commonly reported big barriers to sole- versus co-participation in physical activity.

5.6 Results

5.6.1 Participants Characteristics

The majority of the people with MS were female (76.9%) with a mean age of 54.5 ± 10.6 years, diagnosed with relapsing-remitting MS (51.2%). Importantly, the mean Patient Determined Disease Step score was 5.0 ± 1.4, indicating disability severe enough to require use of a cane or bilateral support for ambulation. The majority of the caregivers were male (63.0%), spouses (73.9%) who had been providing assistance to a person with MS for an average of 9.4 ± 7.1 years. Across the sample, the majority of the participants had ≥ college degree (59.7%), was not working (50.8%), and lived in medium/large urban population centers (68.5%). Table 5-D shows the characteristics of the respondents.
<table>
<thead>
<tr>
<th>Variable</th>
<th>People with MS (n=78)</th>
<th>Caregivers (n=46)</th>
<th>χ²/t-test</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>54.5 (10.6)</td>
<td>51.6 (8.7)</td>
<td>1.6</td>
<td>0.11</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>18.0 (23.1)</td>
<td>29.0 (63.0)</td>
<td>19.6</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Female</td>
<td>60.0 (76.9)</td>
<td>17.0 (37.0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; college</td>
<td>37.0 (47.4)</td>
<td>13.0 (28.3)</td>
<td>4.4</td>
<td>0.04</td>
</tr>
<tr>
<td>≥ college</td>
<td>41.0 (52.6)</td>
<td>33.0 (71.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living situation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living alone</td>
<td>27.0 (34.6)</td>
<td>8.0 (17.4)</td>
<td>4.2</td>
<td>0.04</td>
</tr>
<tr>
<td>Living with someone else</td>
<td>51.0 (65.4)</td>
<td>38.0 (82.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of community</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Small town/rural area</td>
<td>28.0 (35.9)</td>
<td>11.0 (23.9)</td>
<td>1.9</td>
<td>0.17</td>
</tr>
<tr>
<td>Medium/large urban center</td>
<td>50.0 (64.1)</td>
<td>35.0 (76.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;50,000</td>
<td>54.0 (69.2)</td>
<td>27.0 (58.7)</td>
<td>1.4</td>
<td>0.23</td>
</tr>
<tr>
<td>≥50,000</td>
<td>24.0 (30.8)</td>
<td>19.0 (41.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comorbidity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No comorbid condition</td>
<td>45.0 (57.7)</td>
<td>23.0 (50.0)</td>
<td>0.7</td>
<td>0.41</td>
</tr>
<tr>
<td>≥ 1 comorbid condition</td>
<td>33.0 (42.3)</td>
<td>23.0 (50.0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meeting Physical Activity Guidelines</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7.0 (9.0)</td>
<td>12.0 (26.1)</td>
<td>6.5</td>
<td>0.01</td>
</tr>
<tr>
<td>No</td>
<td>71.0 (91.0)</td>
<td>34.0 (73.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor to fair</td>
<td>27.0 (34.6)</td>
<td>21.0 (45.7)</td>
<td>1.5</td>
<td>0.22</td>
</tr>
<tr>
<td>Good to excellent</td>
<td>51.0 (65.4)</td>
<td>25.0 (54.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of MS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RRMS</td>
<td>40.0 (51.2)</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PPMS</td>
<td>8.0 (10.3)</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SPMS</td>
<td>21.0 (26.9)</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PRMS</td>
<td>3.0 (3.8)</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient Determined Disease Steps</td>
<td>5.0 (1.4)</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disease duration (years)</td>
<td>14.7 (10.2)</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship to people with MS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>-</td>
<td>34.0 (73.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-spouse</td>
<td>-</td>
<td>12.0 (26.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years since caregiving</td>
<td>-</td>
<td>9.4 (7.1)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

RRMS, relapsing remitting MS; PPMS, primary progressive MS; SPMS, secondary progressive MS; PRMS, progressive relapsing MS.
5.6.2 Current physical activity

Only 15.3% of the total sample was meeting the Canadian Physical Activity Guidelines. Figure 5-B presents the activities in which participants routinely engage. As shown in the figure, the top three commonly identified activities among people with MS were brisk walking (70%), gardening (35%) and strength training exercises (32%). Among the caregivers, household chores (70%), brisk walking (52%) and gardening (41%) were the three most commonly reported activities.
Figure 5-B. Activities in which the participants routinely engage
5.6.3 The Need Index for people with MS and their caregivers

Table 5-E presents the Need Indexes for people with MS and caregivers. Among the people with MS, the highest priorities, based on a Need Index ≥50 were: 1) information about available resources to support physical activity participation (Need Index = 76.6); 2) programs that support joint participation of people with MS and family caregivers in physical activity (Need Index = 62.0); 3) programs that have facilitators who have adequate MS specific knowledge and training (Need Index = 52.0); and 4) programs that have affordable total cost of participation (Need Index = 50.7). Among the caregivers, the highest priorities, based on a Need Index >50% were: 1) programs that support joint participation of people with MS and family caregivers in physical activity (Need Index = 68.9); 2) programs that provide opportunities to learn about options for incorporating physical activity into daily life (Need Index = 60.0); 3) programs that have affordable total cost of participation (Need Index = 52.3); and 4) information about available resources to support physical activity participation (Need Index = 52.3).

As shown in the table, three items with Need Index >50 were identified by both groups. These items were the need for: 1) information about available resources to support physical activity participation (Need Index for people with MS = 76.6; Need Index for caregivers = 52.3); 2) programs that support joint participation of people with MS and family caregivers in physical activity (Need Index for people with MS = 62.0, Need Index for caregivers = 68.9); and 3) programs that have affordable total cost of participation (Need Index for people with MS = 50.7, Need Index for caregivers = 52.3).
<table>
<thead>
<tr>
<th>Community Resources</th>
<th>People with MS</th>
<th>Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Information about available resources to support physical activity participation</strong></td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>(e.g. publicity and advertisement of programs, information on fee assistance opportunities etc.)</td>
<td>76.6</td>
<td>52.3</td>
</tr>
<tr>
<td>Programs that support joint participation of people with MS and family caregivers in physical activity (i.e., both groups can benefit from and enjoy the program)</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>62.0</td>
<td>68.9</td>
</tr>
<tr>
<td>Programs that have facilitators who have adequate MS specific knowledge and training</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>52.0</td>
<td>27.3</td>
</tr>
<tr>
<td>Programs that have affordable total cost of participation (e.g., parking, membership fees etc.)</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>50.7</td>
<td>52.3</td>
</tr>
<tr>
<td>Programs that are held in accessible locations (e.g., accessible parking, equipment, bathrooms, lockers etc.)</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>34.6</td>
<td>42.2</td>
</tr>
<tr>
<td>Programs that provide opportunities to learn about options for incorporating physical activity into daily life</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>23.7</td>
<td>60.0</td>
</tr>
<tr>
<td>Programs that increase confidence (self-efficacy) to deal with disease-related problems among people with MS and their caregivers</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>23.4</td>
<td>40.9</td>
</tr>
<tr>
<td>Programs that target the mind and the body</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>22.1</td>
<td>25.0</td>
</tr>
<tr>
<td>Programs that provide people with MS and caregivers with the necessary skills to deal with disease-related problems</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>19.5</td>
<td>43.2</td>
</tr>
<tr>
<td>Programs that are customized and flexible in presentation and delivery (e.g., face-to-face or over the internet, individual or group settings)</td>
<td>10</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>15.6</td>
<td>40.0</td>
</tr>
<tr>
<td>Programs that include a wide variety of relevant options for physical activity participation in the same location</td>
<td>11</td>
<td>12</td>
</tr>
<tr>
<td>Accessible, reliable and safe bus routes to important places such as community recreation centers, shopping areas etc.</td>
<td>12</td>
<td>10</td>
</tr>
<tr>
<td>Walking and biking trails that form a viable transportation option to and from activities.</td>
<td>13</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>5.1</td>
<td>2.3</td>
</tr>
</tbody>
</table>
5.6.4 Factors associated with each of the three prioritized need items

Parameter estimates, odds ratios, 95% confidence intervals, and p-values of the logistic regression models for each of the three prioritized need items are shown in table 5-F. Variance Inflation Factor values were below 10 indicating that the variables had independent effects within each model. Each of the models fit the data well as shown by Hosmer and Lemeshow Goodness-of-fit test, which produced p-values of 1.0, 1.0 and 0.30 respectively.

5.6.4.1 Information about available resources to support physical activity participation

The model with people with MS and their caregivers together included two enabling factors (i.e., living situation and type of community). There were no significant predisposing or need factors in this model. As shown in table 5-F, individuals who were living alone were more likely to report the need for information about available resources to support physical activity participation (odds ratio = 3.7 [1.3-10.4]) than individuals who were living with someone else. Compared with individuals who lived in medium/large urban areas, those who resided in rural areas and small towns were more likely to report perceived need for information about available resources to support physical activity participation (odds ratio =7.0 [2.2-22.3]). The results of the model with only people with MS were generally consistent with the results of the model with people with MS and their caregivers together. However, in the model that included only caregivers, no enabling, predisposing or need factors emerged as significant factors.

5.6.4.2 Programs that support joint participation of people with MS and caregivers in physical activity

The model with people with MS and their caregivers together included one predisposing characteristic (i.e., education), one enabling factor (i.e., marital status), and one health need factor (i.e., comorbidity status). As shown in table 5-F, individuals who reported ≥1 comorbid condition were more likely to report a perceived need than those no comorbidity (odds ratio = 2.9 [1.2–6.8]). In addition, individuals who were
married were more likely to report a perceived need than their single counterparts (odds ratio = 3.3 [1.3–8.5]). Finally, individuals with \( \leq \) college degree were more likely to report a perceived need than those with more than college degree (odds ratio = 4.0 [1.6–9.8]). The results of the model with people with MS alone showed that being married and having less than college degree were significantly associated with perceived need (odds ratio = 5.1 [1.5–17.3] and 7.1 [2.1–23.8] respectively. Comorbidity was not significantly associated with perceived need in this model. On the other hand, the model with caregivers alone showed that only comorbidity was associated with perceived need (odds ratio = 6.8 [1.8–25.0]). Education and marital status were not significantly associated with perceived need in this model.

5.6.4.3 Programs that have affordable total cost of participation

The final model included three enabling factors (i.e., type of community, living situation and income) and one need factor one health need factor (i.e., comorbidity status). No predisposing factors were significant. As shown in table 5-F, individuals who reported \( \geq \) 1 comorbid condition were more likely to report a need than those with no comorbidity (odds ratio = 8.1 [3.1–20.9]). In addition, individuals living in rural areas and small towns were more likely to report a perceived need than individuals who resided in medium/large population centers (odds ratio = 5.3 [1.8–15.8]). Compared with individuals who lived with someone else, those who lived alone were more likely to report perceived need (odds ratio = 3.4 [1.1–10.6]). Individuals who earned <$50,000CAD were more likely to report perceived need than those who earned \( \geq $50,000CAD$ (odds ratio = 3.9 [1.4–11.1]). The results of the model with only people with MS showed that having a comorbidity, living alone and earning <$50,000CAD were significantly associated with perceived need (odds ratio = 8.8 [2.0–38.7], 4.3 [1.3–18.1] and 22.3 [3.5–143.5] respectively). Type of community was not significantly associated with perceived need in this model. On the other hand, the model with caregivers alone showed that living in rural areas/small towns and having \( \geq \) 1 comorbid condition were associated with perceived need with odds ratios of 3.4 [2.7–20.9] and 4.2 [2.8–13.5]
respectively. Living situation and income were not significantly associated with perceived need in this model.
Table 5–F. Results from the logistic regression model that included people with MS and their caregivers together

<table>
<thead>
<tr>
<th>Information about available resources</th>
<th>df</th>
<th>Estimate (β)</th>
<th>SE</th>
<th>OR</th>
<th>95% CI</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>1</td>
<td>0.1</td>
<td>0.3</td>
<td>1.2</td>
<td></td>
<td>0.60</td>
</tr>
<tr>
<td>Living situation (ref: living with someone else)</td>
<td>1</td>
<td>1.3</td>
<td>0.5</td>
<td>3.7</td>
<td>1.3</td>
<td>10.4</td>
</tr>
<tr>
<td>Type of community (ref: medium/large urban)</td>
<td>1</td>
<td>2.0</td>
<td>0.6</td>
<td>7.0</td>
<td>2.2</td>
<td>22.3</td>
</tr>
</tbody>
</table>

Programs that support joint participation of people with MS and their caregivers

| Constant | 1  | -1.0          | 0.4| 0.4|        | 0.01|
| Comorbidity (ref: no comorbid condition) | 1  | 1.1          | 0.4| 2.9| 1.2    | 6.8  | 0.02|
| Marital status (ref: single) | 1  | 1.2          | 0.5| 3.3| 1.3    | 8.5  | 0.01|
| Education (ref: >college) | 1  | 1.4          | 0.5| 4.0| 1.6    | 9.8  | 0.003|

Programs that have affordable total cost of participation

| Constant | 1  | -3.4          | 0.7| 0.03|        | <0.001|
| Comorbidity (ref: no comorbid condition) | 1  | 2.1          | 0.5| 8.1| 3.1    | 20.8 | <0.001|
| Living situation (ref: living with someone else) | 1  | 1.2          | 0.6| 3.4| 1.1    | 10.6 | 0.04|
| Type of community (ref: medium/large urban) | 1  | 1.7          | 0.6| 5.3| 1.8    | 15.8 | 0.003|
| Individual income (ref: ≥50,00CAD) | 1  | 1.3          | 0.5| 3.9| 1.4    | 11.1 | 0.01|

Abbreviation: ref, reference; df, degree of freedom; SE, standard error; OR, odds ratio; CI, confidence interval
5.6.5 Barriers to sole-participation and co-participation in physical activity

Figure 5-C shows the most commonly reported barriers to sole- versus co- participation in physical activity. As shown in the figure, almost half of the people with MS identified total cost of participating in a physical activity program and lack of accessible locations as top barriers to both sole- and co- participation in physical activity. About half of the caregivers cited lack of time as a big barrier to sole-participation, while more than 75% cited variability or unpredictability associated with MS, and lack of choice and control over physical activity and level of participation as the top barriers to co-participation.
Figure 5-C. Most commonly reported big barriers to sole- versus co- participation in physical activity
5.7 Discussion

The increasing numbers of community-dwelling people with MS and the negative impact of caregiving on the health of those who support these individuals, as well as the benefits of physical activity on all aspects of health for all people \cite{46-48} highlight the importance of providing these groups with adequate resources for physical activity participation. Our study is unique because it uses the Concerns Report Methodology to identify the most pressing community resources needed to support physical activity participation from the perspective of people with moderate-to-severe MS disability and their caregivers; identifying these needs in these groups has never been done before.

5.7.1 Perceived need for community resources that might support physical activity participation among people with MS and their caregivers

As there has been limited research to date examining the perceived need for community resources in relation to physical activity support, comparing our findings to the extant literature is difficult. Nevertheless, this research was reviewed in the context of the broader needs assessment literature to understand how our findings might align with this body of evidence. The results of this study provide new insights by showing that both people with MS and their caregivers prioritized similar need items related to community resources that might support their participation in physical activity. Specifically, this study identified the need for: 1) information about available resources to support physical activity participation (e.g., publicity and advertisement of programs, information on fee assistance opportunities etc.); 2) programs that support joint participation of people with MS and their caregivers in physical activity (i.e., programs that include components that both groups can benefit from and enjoy); and 3) programs that have affordable total cost of participation (e.g., parking, membership fees etc.). These findings have important implications for future program development.
Specifically, the findings underscore the critical role that program developers, service providers and individuals working in public health systems have to play in ensuring that people with MS and their caregivers have the necessary infrastructure and resources to be physically active in the home and community. Previous researchers have documented the role of healthcare providers in supporting people with MS as they transition from a physically inactive lifestyle to an active one, and our findings reaffirm these studies 49-51. Our findings also suggest that it is time to direct health promotion efforts towards developing innovative models of care that target the health and wellbeing of both people with moderate-to-severe MS disability and their caregivers; a group that has been consistently excluded in previous research. Indeed, emerging evidence from populations with other chronic diseases including Parkinson’s disease and Alzheimer’s disease 52-55 has demonstrated that dyadic physical activity programs are beneficial to the physical and mental health of both partners. Together with our findings, this body of knowledge highlights the potential for dyadic physical activity programs to be an important component of support required by those affected by MS.

5.7.2 Factors associated with perceived need for community resources that might support physical activity participation among people with MS and their caregivers

Although different combinations of factors emerged as drivers of each of the three prioritized need items, overall, we found that income, education, living situation, marital status, and type of community were independently associated with one or more of the need items. Previous research have demonstrated the association between sociodemographic profiles and perceived unmet need for social and health care-related services 56-59. Specifically, these studies have shown that people with chronic diseases including dementia and MS who live alone, in rural areas, have lower educational status or report inadequate income are more likely to have significantly more unmet needs including those related to healthcare services 56-59. Our results were generally consistent with these findings, except in the need for programs that support joint participation of people with MS and their caregivers in physical activity, where those
participants who were married were more likely to report perceived need. Given that these individuals are in cohabitating relationships, it is possible that they spend considerably more time with their partners, are more interested in engaging in joint activities like physical activity than those living alone, and therefore more sensitive to identifying the limitations of available resources to support them in engaging in such activities.

It was interesting to note that in the separate analysis for each of the groups, the factors that emerged as significant drivers of perceived need varied somewhat between people with MS and their caregivers. For instance, while living arrangement, type of community and income were significantly associated with perceived need for information about available resources to support physical activity participation among people with MS, no significant factors emerged among the caregivers. In addition, the model for people with MS alone identified comorbidity, living arrangement and income as important drivers of perceived need for programs that have affordable total costs of participation, while only comorbidity emerged as a significant factor among the caregivers. Overall, the model for caregivers alone yielded less information in terms of significant drivers of perceived need. It is possible that other factors that were not included in the analysis may be driving perceived need particularly among the caregivers. For instance, we did not collect information related to caregiving burden. Previous research suggest that greater burden of care and distress is associated with increased odds of the reporting unmet need for general health services among older adult caregivers. Future larger studies may need to explore in more detail the complexity of factors beyond sociodemographic profiles driving perceived need and the reasons for the differences between people with MS and their caregivers.

Nevertheless, our results show that comorbidity was particularly important for both people with MS and their caregivers. Specifically comorbidity was associated with one of the three prioritized need items for people with MS (i.e., programs that have affordable total costs of participation). In addition, comorbidity emerged as a significant factor associated with two of the three need items among the caregivers (i.e.,
programs that support joint participation in physical activity and programs that have affordable total cost of participation). This finding resonates with previous research in populations with other chronic diseases 60,61. For instance, Thorsen et al. 60 demonstrated that comorbidity is associated with a high level of unmet rehabilitation needs among people with cancer. This finding is important given the high prevalence of comorbidity in MS and the role that physical activity plays in effecting comorbidities among people with the disease 62. Although we are unaware of any studies that have assessed the prevalence of comorbidity in MS caregivers, Gupta and colleagues 63 showed that MS caregivers had higher Charlson Comorbidity Index scores than non-caregivers. Research in other chronic diseases (e.g., dementia) has shown that up to 81.5% of caregivers have one or more comorbid health conditions 64. Given that individuals with comorbidity are typically excluded from physical activity studies in MS 65, our findings further underscore the importance of providing affordable opportunities for both people with MS and their caregivers who have comorbidities to improve their participation in physical activity.

We did not observe associations between other predisposing characteristics (i.e., age, sex) and any of the need items in any of the models. Other studies have demonstrated strong age and sex differences in the experience of need, where younger adults and women are more likely to have unmet needs for health-related care and services 62,68,69. A possible reason for the difference between this study and others may be due to different study designs, populations and data collection methods. For instance, previous studies have included equal or near-equal sex and gender representations whereas our sample comprised majorly of female middle-aged adults.

5.7.3 Barriers to sole- versus co-participation in physical activity

Our findings indicate that the majority of the barriers experienced by people with MS during sole-participation are potentially modifiable impairment-related and logistical factors. These barriers include: high costs of participating in physical activity and lack of accessible locations for physical activity.
programs, consistent with previous research. Our study extends previous research by showing that these factors remained barriers for people with MS when participating together with their caregivers in physical activity. This finding suggests that social support alone may not be enough to overcome barriers associated with physical activity among people with moderate-to-severe MS disability. It is an important finding to highlight, as some researchers have suggested that increased social support, including having someone to exercise with is associated with fewer barriers among people with chronic health conditions. Among the caregivers, the biggest barrier to sole-participation was lack of time. However, when asked about participating in physical activity together with their care-recipients, caregivers identified a variety of MS-related, personal and logistical factors as barriers. These include variability or unpredictability of MS, lack of choice and control over physical activity and level of engagement, and lack of accessible locations. The observed variability in the perception of barriers between people with MS and their caregivers highlight the importance of increased flexibility in developing strategies to enhance caregiver and care recipient participation in physical activity in the presence of their unique barriers.

5.7.4 Physical activity behavior

Our results also show that the majority of the caregivers (70%) identified household chores as routine physical activity. We are unaware of any studies identifying the frequency and types of physical activity self-selected by MS caregivers. Nevertheless, a recent UK study indicated that about 66% of adults in the general population engage in one or more 10min bouts of domestic physical activity daily. The high proportion of caregivers in our study reporting household chores as routine physical activity has significant clinical implications. In an effort to encourage sedentary individuals to engage in at least some physical activity, emphasis has shifted from promoting structured forms of physical activity to lifestyle activities, which can form part of a normal daily routine. It is possible that caregivers in our study may assume that housework is moderate intensity physical activity, and therefore counts towards the recommended 150min/week of moderate-to-vigorous physical activity. However, researchers have shown...
that household chores alone may not be sufficient to provide the health benefits normally associated with regular participation in physical activity \(^72\). Together, these findings suggest the need to provide MS caregivers with information on the benefits of reallocating housework time to alternate light or moderate-to-vigorous physical activity and the tools to appropriately quantify intensity of physical activity in order to ensure that they are indeed engaging at the level that is associated with health benefits.

### 5.7.5 Limitations

Findings of the current study should be treated as exploratory and must be viewed in light of several limitations. First, we recruited people with MS and caregivers separately rather than together as dyads. While this strategy limited the possibility of losing interested individuals by giving people with MS the choice to participate independent of their caregivers and vice-versa, it influenced our ability to study possible interdependent processes within the dyads. For instance, it would be interesting to explore how the perceived need of the people with MS influences the need perception of their family caregivers and vice versa. In addition, our sample was primarily made up of middle-aged women, thus our results may not be generalizable to individuals of other age groups or to men. Some of the confidence limits are wide suggesting that the results may not be a true representation of the population. Future studies should include a larger sample with equal sex and age group representation. The fourth limitation relates to the use of online survey methods. Although high Internet usage have been documented among people with MS and their caregivers previously, it is possible that this data collection method may introduce a sample bias, where only those individuals with access and skills to complete this survey online were interested in our study. In addition, the use of self-reported questionnaires is subject to recall bias. Finally, the cross-sectional study design precludes the ability to comment on the consistency of the identified needs and barriers over time.
5.8 Conclusion

This study identified community resources that might support people with MS and their caregivers to participate in physical activity. The results of the study highlight the need for a multilevel resource that incorporates affordable options for exercising together and innovative methods of outreach to people with MS who have moderate-to-severe disability and the caregivers who support those individuals. Comorbidity and the living context (living alone, residing in a rural area/small town) were common factors associated with perceived need among both people with MS and their caregivers. These factors may provide potential targets for physical activity programming support and intervention approaches.

Declaration of Interest Statement

This work was funded, in part, by a Doctoral Studentship from the Multiple Sclerosis Society of Canada awarded to AF

Implications

- Physical activity has emerged as an alternative approach for managing the consequences of MS. However people with MS who have moderate-to-severe disability and their caregivers are rarely targeted in physical activity studies.
- Clinicians and individuals working in public health systems need to be aware of the most important community resources that might support a physically active lifestyle among these groups.
- This study has demonstrated the need for a multilevel resource that incorporates affordable options for exercising together and innovative methods of outreach to people with MS who have moderate-to-severe disability and caregivers who support those individuals.
5.9 References


21. Black BS, Johnston D, Rabins PV, Morrison A, Lyketsos C, Samus QM. Unmet needs of community-residing persons with dementia and their informal caregivers: Findings from the


Chapter 6 Discussion

6.1 Introduction

The goal of this chapter is to consolidate the dissertation document by synthesizing the findings from the three studies conducted as part of this work and highlighting future research directions. This chapter also includes a brief reflection on using the Developmental Contextual Coping Model as a theoretical framework and the Concerns Report Methodology as an overarching methodology. Finally, the limitations of the research are highlighted before giving the final conclusion.

6.2 Revisiting the overarching goal of this dissertation

As highlighted in chapter two, evidence collected over the past few years suggests that people with MS engage in relatively low levels of physical activity compared with their apparently healthy counterparts and people with other chronic diseases. Lower levels of physical activity have been associated with greater neurological impairment, progressive accumulation of disability and increased risk of comorbidity among people with MS. Consequently, over the last few decades, there has been substantial attention focused on developing interventions to improve the physical activity level among people with MS. Researchers have also demonstrated associated intervention benefits of improved physical and mental health, as well as overall quality of life. However, MS researchers have been reluctant to include people with MS who have moderate-to-severe disability in physical activity interventions. These individuals represent a unique subset of the MS population due to their complicated symptom profiles and the need for specialized supports. Given the evidence that disease-modifying drugs are only minimally effective in slowing eventual progression of disability in MS, and the well documented benefits of physical activity among people with lower disability levels, it is critical to now examine whether there is sufficient evidence to support the inclusion of physical activity in the comprehensive management and care of those affected by moderate-to-severe MS disability.
Another important gap in current research is the lack of information about physical activity participation and benefits for MS caregivers. Caregivers are a significant source of support for their loved ones with MS, and to healthcare systems that are overburdened and under resourced. Yet, these caregivers are often invisible within the larger MS care system. As the prevalence of MS is projected to increase into the future, and people with MS live longer with their disease, caregivers will be increasingly called upon to be partners in delivering care across the disease trajectory. Thus, healthcare systems will be faced not only with the responsibility of providing care to a growing number of people with MS with progressive disability, but also need to pay critical attention to addressing the needs of MS caregivers.

Without supporting MS caregivers in maintaining their own health and wellbeing, MS care systems will not truly be embracing the standards of client and family centered care.

Considering the interdependence between MS caregivers and care-recipients, there may be potential utility to a dyadic physical activity intervention for dyads affected by moderate-to-severe MS disability. It is an exciting time for developing such an intervention given the new focus on reallocating sedentary time to alternative activities (i.e., LPA or MVPA) and increased attention to ensuring that evidence-based interventions are broadly disseminated for maximal public health impact.

A comprehensive needs assessment is a critical first step to developing interventions, as it gathers information that will ensure that the interventions are theoretically-driven, evidence-based and likely to succeed. Therefore, the overarching goal of this dissertation was to determine if there is sufficient evidence to support the development of dyadic physical activity intervention for people with moderate-to-severe MS disability and their family caregivers.
6.3 Key findings

This section is focused specifically on discussing the key findings and how they have challenged and/or extended current knowledge. The findings of each study are discussed in detail in the context of existing literature in the associated chapters (i.e., Chapters three through five).

6.3.1 Focus Group Study – Chapter 3

The first dissertation study reported a qualitative exploration of shared perceptions about physical activity in an attempt to advance our understanding of this phenomenon among MS caregiver care-recipient dyads. The study highlighted a novel finding in relation to the influence of mutuality on the dyads’ level of participation in physical activity. The dyads described physical activity an interpersonal experience, with care-recipients and caregivers sharing similar struggles, frustrations and adjustments when trying to be physically active. From a theoretical perspective, this finding provides support for the Developmental Contextual Coping Model’s\(^1\) conceptualization of interdependence in the context of MS, and challenges previous qualitative physical activity studies that have focused on capturing the perspectives of either people with MS\(^ {36,37}\) or their caregivers independently\(^ {38}\).

This study also contributes to the literature by showing that structured and unstructured physical activity are not perceived as mutually exclusive, and that each partner in the MS dyad can go back and forth along the unstructured-to-structured continuum depending on current circumstances. From a practical perspective, this finding suggests that interventions should not solely focus on promoting structured exercise, but also encourage lifestyle physical activity (i.e., daily accumulation of self-selected activities) while taking the needs of both caregivers and care-recipients into consideration. Previous physical activity interventions have typically focused on structured exercise training exclusively, but the possibility of long-term success has been plagued by a lack of adherence\(^ {11-14,16,39-41}\). Consequently, there have been
calls for a paradigm shift towards including lifestyle physical activity as a partner alongside exercise training in comprehensive MS care \textsuperscript{42}. Indeed, this study supports the need for a paradigm shift and further provides insight into the ideal design of a dyadic lifestyle physical activity intervention from the perspective of dyads with MS. For instance, flexibility and control over choice of physical activity and level of engagement based on different exercise capacities were identified as ideal components that are likely to facilitate long-term dyadic participation.

By involving people with MS together with their caregivers as co-participants in this study, a collaborative partnership was created between the participants and the researchers, where the dyads identified unique issues, concerns, and needs related to their physical activity participation, and discussed possible solutions that acknowledged current community resources. In this way, the first manuscript helped direct the research to areas where deficiencies were perceived and formed the building blocks upon which subsequent manuscripts within the dissertation were built.

\textbf{6.3.2 Physical Activity Assessment Study – Chapter 4}

Given that the participants in the first study described physical activity as an interpersonal experience, the second dissertation study sought to objectively examine the interdependence between dyadic physical activity patterns (i.e., time spent in sedentary behavior, LPA and MVPA) among dyads affected by moderate-to-severe MS disability. A simultaneous accelerometry assessment of physical activity among 14 matched caregiver care-recipient dyads was carried out. By collecting data from the two partners simultaneously, we sought to test interdependence using the dyad as the unit of analysis in accordance with the analytical framework of the APIM \textsuperscript{43}.

Despite findings from this study failing to demonstrate interdependence in physical activity patterns among this small sample of dyads, the findings showed that both people with moderate-to-severe MS
disability and their caregivers were far below the public health guidelines of 150 min/week of MVPA for the general population. Participants in this study also did not meet the daily public health recommendations of 10,000 steps/day. This work extends previous research \(^7,44,45\) by uniquely confirming low levels of physical activity among dyads affected by moderate-to-severe MS disability. Interestingly, while MS caregivers may take on a wide range of household and caregiving activities \(^{46}\) that could potentially contribute to the daily accumulation of physical activity, they were still below levels of physical activity recommended for the general population.

From a practical perspective, the results of this study suggests that physical activity interventions that target a reduction in sedentariness and increase in physical activity behavior may be important for dyads affected by moderate-to-severe MS disability. Indeed, the recent research demonstrating health benefits of sedentary time reallocation to alternative activities (i.e., LPA or MVPA) among the general adult population\(^{31,33,47-49}\) may be worth consideration by MS researchers and clinicians. Although the effect of MVPA in MS is well documented, the research on sedentary time reallocation to LPA suggests that MS researchers may need to focus attention on evaluating the health effects of LPA and the relationship to health outcomes among people with MS. If supported by research evidence, then targeting an increase in at least LPA may be a practical and achievable way to induce change in physical activity behaviors among dyads with moderate-to-severe MS disability rather than seeking to increase levels of MVPA, which may be more challenging.

The findings from the first and second dissertation studies suggest that regular physical activity participation remains a serious challenge for dyads affected by moderate-to-severe MS disability, and underscore the importance of identifying resources within the community that can support them in transitioning from a physically inactive lifestyle to an active one.
6.3.3 Concerns Report Survey – Chapter 5

The final dissertation study sought to identify the most pressing needs for community resources to support physical activity participation among people with MS who have moderate-to-severe disability and their caregivers. The study also sought to identify determinants of perceived need and the barriers to sole-versus co-participation in physical activity among the target groups. The results show three pressing need items that were identified by both people with MS and their caregivers. These need items were related to: 1) information about available resources to support physical activity participation; 2) programs that support joint participation of people with MS and caregivers in physical activity; and 3) programs that total cost of participation, which are affordable.

A broad range of factors was significantly associated with one or more of the need items and when these factors were viewed within the conceptual model of Andersen and Newman, all the three factor groups (predisposing, enabling and health need) played a role in the perception of need. Interestingly, comorbidity status was associated with two of the three prioritized need items (i.e., programs that support joint participation of people with MS and their caregivers in physical activity; and programs that have total cost of participation, which are affordable). The finding is noteworthy given the high prevalence of comorbidity in MS and the potential role that physical activity can play in effecting comorbidities in the general population. From a practical perspective, the finding further highlights the importance of extending physical activity programs to MS dyads who may have comorbidities to enable them access resources to improve physical activity participation, consistent with previous studies that have called for MS researchers to prioritize the inclusion of participants with comorbidities in rehabilitation interventions.

We took a novel approach to identifying physical activity barriers by focusing on barriers with potential relevance to both people with MS and their caregivers, and those that could be targeted through the design
and logistics of community-based dyadic physical activity interventions. The results show the variability in barriers to sole- versus co-participation in physical activity among people with MS and their caregivers. Specifically, people with MS reported more personal factors, while the caregivers cited a combination of personal and environmental barriers. This work extends the first dissertation study and previous research on personal and health system barriers influencing participation of people with MS in physical activity, and suggests that efforts to promote physical activity in dyads affected by moderate-to-severe MS disability should include personalized strategies to manage care-recipients and caregivers unique barriers.

Together, the studies conducted within this dissertation have established that a multilevel resource that incorporates affordable options for exercising together and innovative methods of information dissemination and outreach to the people with moderate-to-severe MS disability is needed. The studies have also indicated that the short – and long – term success of dyadic physical activity interventions in MS may be contingent upon adequate diminution of care-recipients and caregivers unique barriers.

6.4 Future research directions

Synthesizing the findings from the three studies included in this dissertation has raised at least three possible areas of interest for future research, which are discussed below.

6.4.1 Improving the health of MS caregivers

The presence of caregiver stress and changes in physical and psychosocial health among MS caregivers has been well-documented. Caregivers who perceive illness interference arising from caregiving-related stressors become less able to assist their care-recipients in maintaining independence and associated life roles. Considering that current models of MS care delivery are dependent on caregivers as partners in care, researchers, program developers and policy makers worldwide are beginning to
recognize the need to sustain the health and wellbeing of MS caregivers\textsuperscript{58-60}. Nevertheless, existing interventions (e.g. psychosocial and educational interventions) aimed at supporting MS caregivers in their role have focused on: i) building skills that enable caregivers to manage care-related stressors; and ii) improving mental health outcomes\textsuperscript{61,62}. This dissertation work is in line with these efforts and suggests that it is now time to explore health-promoting activities in addition to more traditional forms of support for MS caregivers.

Regular participation in physical activity may support MS caregivers in their role by maintaining their mental and physical health so that caregiving becomes less risky to their own wellbeing. Previous studies have highlighted the importance of regular participation in physical activity among caregivers of people with Alzheimer’s disease and cancer. For instance, Farran et al.\textsuperscript{63}, Hill et al.\textsuperscript{64}, and Martin et al.\textsuperscript{65} reported improved quality of life, decreased levels of depression and anxiety, and increased sleep quality among caregivers participating in physical activity interventions. All of these benefits suggest improved wellbeing, which in turn, may contribute to improved ability to provide care to a loved one with a chronic disease. Caregivers in the study by Cuthbert et al.\textsuperscript{66} further reported feeling more confident in their ability to cope and take control, and more resilient in dealing with other life challenges in addition to caregiving. These same caregivers described learning how to incorporate regular physical activity and other healthy behaviors into their lives after the intervention. In line with these studies and our findings, this body of evidence highlights the potential for physical activity to be an important component of support required by MS caregivers, a group that has been consistently marginalized in previous physical activity research in MS.
6.4.2 Developing the evidence base for lifestyle physical activity interventions in moderate-to-severe MS

As physical activity research in MS continues to evolve, high quality trials will be needed to further develop the evidence base for lifestyle physical activity interventions for people with moderate-to-severe MS disability. It will also be important to determine the minimum amount of physical activity that can be prescribed for health benefits for these individuals. Future large studies may wish to confirm whether or not the activities commonly identified by the dyads in this dissertation as part of their everyday life improve physical activity level, and contribute to physical fitness and overall quality of life. In other words, researchers would need to ascertain whether or not these accumulated routine activities performed over a period of a day, week or months might improve wellbeing among the dyads.

Previous researchers have demonstrated that accumulated habitual physical activity of all types improves physical activity levels and cardiovascular risk factors including cardiorespiratory fitness among the general population and those with diabetes and cardiac disease and this would be an interesting avenue for future MS research. In addition, future research should focus on increasing our understanding of how sedentary behavior can be optimally reduced and broken up among MS caregiver care-recipient dyads affected by moderate-to-severe disability. Specifically, it is important to identify what types of behaviors can optimally replace sedentary behavior for health benefits among these individuals. Previous studies in the general population have shown that replacing sedentary behavior with MVPA or even less intense activities such as standing has beneficial health outcomes for the general population, and it would be interesting to determine if these findings are consistent among people with moderate-to-severe MS disability.
6.4.3 Developing and evaluating physical activity interventions for MS dyads

Finally, considering that MS dyads share social and physical environments, a practical approach to manage the disease impact, while efficiently utilizing resources, may be to design a dyadic intervention that supports both people with MS and their caregivers in changing their physical activity behavior. We contend that by participating in physical activity as a team, a dyadic intervention will engage both caregivers and care-recipients as equal and interactive partners coping and working together to improve their own and their partner’s health and wellbeing.

Although still in infancy, there is mounting evidence from other chronic disease contexts including stroke, cancer, Parkinson’s and Alzheimer’s disease \(^{69-74}\) that dyadic physical activity interventions are feasible and acceptable with beneficial effects on the overall health of both partners. For instance, Winters-Stone et al. \(^{70}\) reported improvement in body composition (muscle mass), upper and lower muscle strength, physical activity level and physical functioning (physical performance battery) among dyads with prostate cancer after a dyadic physical activity intervention. In addition, the authors reported feasibility metrics with trial accrual, retention and adherence rates that met or exceeded target goals and the absence of study-related injuries. Badger et al. \(^{72}\) also demonstrated improvement in anxiety among 23 dyads affected by breast cancer after participating in a six-week telephone delivered self-managed physical activity intervention as part of a three arm RCT. Although, Marsden et al. \(^{69}\) observed no statistically significant differences between groups in a dyadic physical activity intervention involving stroke survivors and their caregivers, there was a positive trend in favor of the intervention group for improved perceived overall recovery, six-minute walk test and quality of life. Together with our findings, this body of evidence suggests that the development and evaluation of dyadic physical activity interventions is a timely and important research activity that has the potential to facilitate improved health and wellbeing for dyads affected by MS.
6.5 Features of dyadic physical activity interventions in previous studies

Looking broadly at the dyadic physical activity literature, some features of previous interventions may be relevant in the context of MS (i.e., map closely with the needs of dyads identified in this dissertation work). While it is beyond the scope of this dissertation to provide a review of essential components of effective physical activity interventions, it is important to highlight some of these features because incorporating them into the development of future interventions for MS dyads may increase the likelihood of intervention success.

6.5.1 Use of tailored intervention and outcomes to match participant need

The majority of the studies used tailored intervention strategies, where intervention components were delivered based on the unique characteristics derived from individual assessments of both partners. For instance, Winters-Stone et al. prescribed resistance exercise at a relative intensity tailored to each partner’s baseline capacity rather than requiring both partners to exercise at the same absolute intensity. In this way, the authors ensured that the intervention allowed partners with different capacities to exercise in a dyadic setting. These features are consistent with the ideal intervention described by the dyads in the first dissertation study. For instance, the dyads highlighted the need for MS dyadic physical activity interventions to include individually tailored strategies to overcome unique caregiver care-recipient dyad barriers.

6.5.2 Use of appropriately trained interventionists

The studies suggest that a wide range of interventionists including exercise physiologists, nurses, occupational therapists (OTs) and physiotherapists (PTs) can deliver effective dyadic physical activity interventions. For example, in the study by Winters-Stone et al., an exercise physiologist certified in strength training instruction and with experience training older adults delivered the intervention. On the
other hand, members of a stroke-specific multidisciplinary team consisting of PTs, social workers, nurses and OTs delivered the intervention components in the study by Marsden et al. 69 Nevertheless, a common trend among all the studies was that the interventionists had specific expertise and experience delivering care to the target population and/or had received appropriate training to deliver the intervention content. Similarly, people with MS in this dissertation study also stressed the importance of dyadic physical activity interventions that are delivered by professionals who have adequate MS specific knowledge and training. Indeed, this item was ranked as the third most pressing need among people with MS who participated in the third dissertation study.

6.5.3 Use of specific behavior change techniques

Although none of the previous studies explicitly states the theoretical basis of the interventions, they do incorporate theoretically specified clusters of self-regulatory techniques (e.g. goal setting and review, self-monitoring of behavior, feedback on performance and strategies to maintain long-term behavior change). For example, Marsden et al. 69 incorporated educational sessions on goal setting, understanding stroke risk factors and prevention, as well as strategies for making long-term changes and maintaining healthy behaviors. These features are consistent with findings of the first dissertation study where the dyads described an ideal intervention as one that would include counseling and education sessions to provide advice and information, as well as support development of skills for long-term changes in physical activity behavior. In line with Hagger and Chatzisarantis 75, these findings suggest that selecting and incorporating complimentary components of behavioral change theories may provide researchers with the ability to design a targeted intervention for MS dyads.

There are at least two potential theories that may lend important ideas about how to conceptualize the design of physical activity interventions for MS caregiver care recipient dyads: the self-determination theory (SDT) 76 and the health action process approach (HAPA) 77. In brief, the SDT is a paradigm of
human motivation that distinguishes between autonomous and controlled motivation. Although both autonomous and controlled motivation influence behavior, they each lead to a different outcome, with autonomous motivation leading to greater commitment and long-standing maintenance of behavior. SDT posits that individuals are more likely to exhibit autonomous motivation for health promoting activities such as physical activity when three basic psychological needs are supported: autonomy (i.e. the need to feel that one can choose one’s behaviors), competence (the need to feel competent and confident) and relatedness (the need to feel connected to and understood by others). In contrast, HAPA includes two implicit phases (motivational and volitional), which encompass the behavior change process from pre-intention to action initiation and maintenance. It also provides a framework to categorize individuals into phases of change and indicates how to overcome barriers that hinder transition to the next phase as individuals move towards maintenance of physical activity behavior. Researchers have shown that intervention components underpinned by theories such as the SDT and HAPA are more effective than those without a theoretical basis.  

6.6 Reflection on and critique of the theoretical framework and methodology

6.6.1 Theoretical framework

As highlighted in chapter 2, the Developmental Contextual Coping Model provides a framework for understanding how dyadic processes may vary across the adult lifespan and disease trajectory for those affected by chronic disease. According to the model, one partner’s stress experiences are not independent of the other partner’s stress, and coping is conceptualized as a relational and interdependent process. Emphasis is placed on dyadic appraisal of shared stressors (i.e., the stressor is “ours”) rather than an individual appraisal (i.e., the stressor is “mine”), and on the use of collaborative coping strategies.

Our experience of using the Developmental Contextual Coping Model suggests that it may be a valuable tool for changing the way therapeutic interventions including physical activity are offered to people with
moderate-to-severe MS disability. Currently, MS caregivers are usually involved sporadically, if at all, in the therapeutic process, and typically only in a supportive role. When our findings are viewed through the lens of the Developmental Contextual Coping Model, they suggest that therapists should not only involve MS caregivers in providing support, but should invite both partners to engage in collaborative coping strategies, as both are equally affected by the stressor (i.e., the disease). In addition, therapists need to identify ways of supporting the dyads to develop a collectivist orientation towards the appraisal of the disease as a “we-disease” and stressors as “we-stressors”, and teach both partners how to collaborate efficiently together to identify options for reducing the impact of these stressors.

6.6.2 Methodology

Participatory action research has been traditionally conceptualized as a continuum of possible research designs. At one end of the continuum is bottom-up design, where the questions and issues are defined by community members who share a common problem rather than by researchers. Although community members may choose to bring researchers with unique skills into the research project, they retain control of the design and direction of the research. At the other end of the continuum are projects initiated by researchers who include members of the community as participants in the research, consistent with a top-down approach.

While it is simple to view these two approaches as fundamentally different, the associated criticisms of each design highlight the potential utility of hybridization of approaches. Top-down approaches can lack legitimacy and ownership in the eyes of the community members, which prohibit meaningful engagement in the research process and outcomes. While a bottom-up approach enhances the legitimacy of the research outcomes, it is often criticized for lacking quality and rigor. Hybridization addresses some of these limitations by proving opportunities for the enhancement of mutual learning and sharing of
experiences between the researchers and the community members, which may ultimately result in the development of more meaningful research outcomes.

Our experience suggests that the Concerns Report Methodology is flexible and easy to use as a hybrid participatory action research approach to needs assessment. For instance, the impetus for this dissertation work came from researchers with experience of chronic disease and MS management, who developed the idea of a research project that would include client participation. Thus, the choice of a target population and the design of the project were generated and initiated by the research team rather than a community group composed of people with MS and their caregivers, consistent with a top-down approach. Nevertheless, the focus group meetings provided ample opportunities to explore physical activity-related issues that the dyads felt were important and to discuss what might be done about them. In addition, representatives of the target population were actively engaged in the development process of the survey instruments in a participatory manner by proposing items based on their own experiences of physical activity. Beyond our commitment to improving physical activity participation among MS dyads, we did not dictate any other outcomes of the project, which was consistent with the bottom-down design. In other words, our intent was to allow issues to emerge throughout the course of the research rather than imposing issues in an a priori fashion. We believed that this approach would give the dyads that participated the most freedom to control the direction the research took.

Overall, the research was a success despite ultimately emphasizing a participatory rather than an action aspect of the Concerns Report Methodology i.e., needs and concerns were identified without developing action plans or evaluating the outcomes of actions taken to address the needs. Nevertheless, there are several points worth highlighting for future researchers who may be interested in using the Concerns Report Methodology as a hybrid participatory action research needs assessment process. First, the qualitative phase of the Concerns Report Methodology was particularly responsive to giving voice to the stakeholders’ perspectives and generating rich data to highlight the wide variability in current local
situations. For example, while some dyads spoke of accessing available community services to support their participation in physical activity, others were currently looking for services that were not available in their communities. Thus, the dyads were able to share their knowledge of the conditions of the existing community supports and the issues that they felt were needs or gaps based on their experiences.

This phase also allowed the researcher to gain a greater understanding of some of the potential challenges that may be associated with delivery of community resources to support joint physical activity participation of people with moderate-to-severe MS disability and their family caregivers. For instance, the importance of community resources that consider individual preferences and capacities of each partner was highlighted. The dyads also felt it was essential to give both partners equal opportunities for physical activity participation and benefit. Successfully incorporating preferences of both people with moderate-to-severe MS disability and their caregivers into existing physical activity programs may be a lengthy and resource intensive process. In this way, there was enhancement of mutual learning and sharing of experiences between the researchers and the community members, which we anticipate will result in the development of more meaningful outcomes related to strategies to address the identified needs.

The quantitative phase strengthened the partnerships that had developed between the researchers and the participants during the focus groups and gave community members the opportunity to make key contributions to the needs assessment process. Indeed, five of the focus group participants were directly involved in developing the final concerns report surveys to reflect their potential needs. During this phase, the long list of issues identified from the focus groups had to be systematically reduced to make a workable shortlist of items for the surveys. Where there were strong similarities in content, some items had to be combined, which at times created tension between the researchers and the stakeholders in terms of producing broader themes and preserving the specificity and authenticity of uncombined items. An approach was taken that tried to balance these two issues so as to maintain some of the richness provided
by the qualitative data and the details that would be useful in the development of any future intervention. Despite possible tensions, the inclusion of the community members as collaborators provided comprehensive insight; the individuals added understanding from their own life, thereby fostering deeper discussions during the survey development meeting. In this way, the Concerns Report Methodology process ensured the relevance of issues selected for the surveys and improved clarity about the important needs of people with MS and their caregivers. Overall, by involving people with MS and caregivers early on and throughout the research process in a participatory manner, participants were empowered to take ownership, identify physical activity related issues that are relevant to them and identify potential ways of addressing these issues.

Nevertheless, there are a few methodological drawbacks that are worth highlighting. First, the Concerns Report Methodology does not typically include a discussion around research methods. Thus, it does not provide information about establishing the reliability and validity of the survey instruments. Although we pilot tested the survey instruments to establish aspects of face and content validity, further psychometric evaluation was not carried out. In addition, the Concerns Report Methodology does not use scientific sampling since the goal is to involve as many people with MS and caregivers as possible in the agenda-building process. However, limited access to a representative sample of the target population can pose a threat to the generalizability of the findings and products of survey data. For instance, in this dissertation, MS caregivers were a difficult population to access despite the use of a “canvass” approach that included several recruitment strategies. If we use the Concerns Report Methodology again in the future, we will consider including people with MS and caregivers in ongoing implementation meetings with the research team to provide complementary advice on aspects of study implementation including dealing with recruitment and data collection issues. Given the time demands on caregivers of people with moderate-to-severe MS disability, it will be prudent to consider if specific meetings or parts of meetings would benefit from caregiver input.

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6.7 Limitations of the dissertation

Although the studies included in this dissertation address a clear void in current research regarding physical activity promotion among MS caregiver care-recipient dyads affected by moderate-to-severe disability, there are at least four limitations to this body of work. One of the primary limitations of this research relates to our inability to carry out a truly participatory action research process as exemplified in the Concerns Report Methodology. Implementing all the phases in the Concerns Report Methodology process can last several years. Because of the dissertation timeline and budgetary constraints, only phases one through three were carried out, which ultimately emphasized the participatory over the action aspect and impacts our ability to examine the utility of the action phases of the Concerns Report Methodology in this context. Nevertheless, a long-term goal of this research is to develop interventions to address the identified needs and examine the feasibility, and implementation of these interventions.

Another limitation is the relatively small sample of participants, particularly in the second and third dissertation studies. This work targeted a specific subset of the MS population, individuals with moderate-to-severe disability and their family caregivers. Due to the highly specific target group, the population from which the sample was drawn was very limited. The specificity of this sample also limits the generalizability to dyads with lower disability levels.

The final limitation of the current work is the cross-sectional nature of the studies. Cross-sectional studies have the advantages of being relatively low in costs and time commitment, yet they have the limitations that temporal causations cannot be established or inferences made. Thus, the use of a cross-sectional design impacts our ability to comment on the consistency of the findings over time.
6.8 Final conclusions

The importance of supporting people with MS and caregivers throughout the trajectory of the disease cannot be understated. The challenges of the disease and its consequences are substantial. This research was guided by the notion that an understanding of the health of one partner is incomplete without considering the health of the other person in the dyad. This interdependence is a reflection of the lived experience of those affected by chronic diseases such as MS. Taken together, the findings have demonstrated the wealth of information that can be gleaned from exploring physical activity from the perspectives of people with MS who have moderate-to-severe disability and the family caregivers who support them. This dissertation has shown that a comprehensive view of care recipient and caregiver health may be useful for understanding factors that influence their wellbeing and for designing interventions to support them. Finally, the findings suggest that the development and evaluation of a multilevel resource that incorporates affordable options for exercising together and innovative methods of outreach to people with MS who have moderate-to-severe disability and their family caregivers is a timely and important research activity that has the potential to facilitate improved health for these groups.
### References


Appendix A: Manuscripts 1 and 2 ethics approval

QUEEN’S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING HOSPITALS RESEARCH ETHICS BOARD-DELEGATED REVIEW
February 11, 2015

Miss Afolasade Farotimi
School of Rehabilitation Therapy
Queen’s University

Dear Miss Farotimi

Study Title: REH-610-15 A needs assessment to inform the development of a dyadic physical activity program for people with multiple sclerosis who have moderate to severe disability and their caregivers
File # 6014723

Co-Investigators: Dr. T. Parsons, Dr. A. Latimer-Cheung, Dr. M. Finlayson

I am writing to acknowledge receipt of your recent ethics submission. We have examined the protocol (Version 1 – Jan. 26, 2015), supervisor letter of approval, Aim 1 and Aim 2 – telephone recruitment script, email recruit script, recruitment flyer, print advertisement, meeting presentation script, scripts for calls from potential participants, focus group guide, focus group – MS participant questionnaires and surveys, focus group – Friends and Family Members of People with MS questionnaires and surveys and information/consent forms for your project (as stated above) and consider it to be ethically acceptable. This approval is valid for one year from the date of the Chair’s signature below. This approval will be reported to the Research Ethics Board. Please attend carefully to the following listing of ethics requirements you must fulfill over the course of your study:

Reporting of Amendments: If there are any changes to your study (e.g. consent, protocol, study procedures, etc.), you must submit an amendment to the Research Ethics Board for approval. Please use event form: HSREB Multi-Use Amendment/Full Board Renewal Form associated with your post review file # 6014723 in your Researcher Portal (https://eservices.queensu.ca/romeo_researcher/)

Reporting of Serious Adverse Events: Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information. Serious Adverse Event forms are located with your post-review file 6014723 in your Researcher Portal (https://eservices.queensu.ca/romeo_researcher/)

Reporting of Complaints: Any complaints made by participants or persons acting on behalf of participants must be reported to the Research Ethics Board within 7 days of becoming aware of the complaint. Note: All documents supplied to participants must have the contact information for the Research Ethics Board.

Annual Renewal: Prior to the expiration of your approval (which is one year from the date of the Chair’s signature below), you will be reminded to submit your renewal form along with any new changes or amendments you wish to make to your study. If there have been no major changes to your protocol, your approval may be renewed for another year.

Yours sincerely,

Albert J. Clark
Chair, Health Sciences Research Ethics Board
February 11, 2015

Investigators please note that if your trial is registered by the sponsor, you must take responsibility to ensure that the registration information is accurate and complete
Appendix B: Manuscript 1 letter of information and consent form

Letter of Information

Project title: A needs assessment to inform the development of a dyadic physical activity program for people with MS who have moderate to severe disability and their caregivers

Researchers:
Ms. Afolasade Farotimi, School of Rehabilitation Therapy, Queen’s University
Dr. Marcia Finlayson, School of Rehabilitation Therapy, Queen’s University
Dr. Amy Latimer, School of Kinesiology & Health Studies, Queen’s University
Dr. Trisha Parsons, School of Rehabilitation Therapy, Queen’s University

What is this study about?
Regular engagement in leisure-time physical activity is beneficial for all people and for people with MS in particular. However, many people with MS who have moderate to severe disability may find it challenging to engage in leisure-time physical activity. Also, caregivers may have limited time and opportunity to engage in leisure-time physical activity due to their caregiving responsibilities. The goal of this study is determine whether there is a need for a program that supports people with MS who have moderate to severe disability and their caregivers to engage in leisure-time physical activity together.

We are inviting you to participate in a focus group because you are a person with MS or a close friend or family member and may have perspectives on leisure-time physical activity.

What procedures are involved?
If you agree to be in this study, we would ask you to:

- Participate in one focus group meeting. A focus group is a discussion with 8-10 other people. During the discussion, we will be asking you to share your views and experiences regarding leisure-time physical activity. We expect that the discussion will take approximately 90 minutes.
- Before the focus group, you will be asked to complete a brief survey, which should take about 10 minutes. The information in this survey will help us describe the people who participated in the discussion (e.g., average age, gender, living situation, etc.)
- We will record the focus group. This recording will only be used to produce a transcription for analysis purposes.
• *(optional)* You may review a short written summary of the discussion of your group. We will prepare and send to you for you to review for accuracy.

**What are the potential risks and discomforts?**
The study has minimal risks. You will be sitting throughout the group but you can get up if you become uncomfortable. Some of the discussions may make you feel uncomfortable because they will make you think the challenges and barriers to staying physically active. The discussions may be hard if you, your close friend or family member is facing these challenges now or has in the past. You can choose not to answer any questions that you don’t want to answer. You can leave the focus group at any time. Before the group, we will explain to everyone that our discussions are confidential and are not to be shared with others who are not in the group. Although we will do everything we can to emphasize confidentiality, we cannot guarantee that others in the group will not share our discussions with others.

**Are there benefits to taking part in the research?**
There are no direct benefits to you from taking part in this research. Your participation in this study would help the researchers understand the experiences and perspectives of people with MS and their caregivers about leisure-time physical activity. Your participation will also provide information that may inform the development of programs to support regular engagement in leisure-time physical activity for people with MS and their caregivers.

**Is my participation voluntary?**
Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the Queen’s University or any organization through which you heard about this study. If you decide to participate, you are free to withdraw at any time without affecting those relationships. You may refuse to answer any questions you don’t want to answer and still remain in the study.

**What will happen to my responses?**
We will keep your responses confidential. Only the investigators (Ms. Farotimi and Drs. Finlayson, Parsons and Latimer) will have access to the transcription and the survey information. When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity. This information will be disclosed to others only with your permission or as required by law.

All the study information collected from you will be stored in a safe and locked location in the Multiple Sclerosis Rehabilitation Research Suite of Dr. Marcia Finlayson in
Botterell Hall at Queen’s University. It will be kept for 10 years after it is analyzed and published. Your name will not appear on any documents related to your participation in this study. We will identify you by a code in order to maintain your confidentiality.

**Will I be compensated for my participation?**
You will not receive any payment for your participation in this study.

**What if I have concerns?**
Any questions about study participation may be directed to Ms. Farotimi at the MS Rehabilitation Research Suite on 1-855-533-3407 toll-free. If you have any concerns about your rights as a research participant please contact Dr. Albert Clark – Chair of the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at 613-533-6081.

Your interest in participating in this research study is greatly appreciated. This study has been granted clearance according to the recommended principles of Canadian ethics guidelines, and Queen’s policies.
Appendix C: Manuscript 1 focus group guide

Focus Group Guide

ID: ........................................................................................................................................
Date: ........................................................................................................................................
   Start time: ............................................................................................................................
   End time: ..............................................................................................................................
Facilitator: ................................................................................................................................
Co-facilitator: ........................................................................................................................

Introduction:

Thank you everyone for coming here today. If you have not already had a chance, please help yourselves to some of the refreshments that we have available on the back table. Please make sure, too, that you make a nametag at the table by the entrance, as it will help us learn your names [tonight/this afternoon/this morning.]

Before we get started, I just need to make sure that everyone has had the chance to complete the surveys. [Researcher scans the room and ensures that everyone has completed these and takes the names of anyone who requires follow up after the meeting.] We appreciate that you have taken the time to fill these in. This information will help us describe the people who participated in our discussions.

You were all sent the Information Letter in advance of today’s meeting. We are happy to answer any question at all that you might have about the research before we get started, whether it is large or small.

[Questions are answered and participants are invited to ask more questions until there is agreement that there are no further questions.]

[Once there are no further questions, the researcher continues the introduction.]

[Tonight/this afternoon/this morning], we are going to be talking about the experiences of leisure-time physical activity in general. We will ask questions related to your understanding of leisure-time physical activity, motivations for and barriers to engaging in leisure-time physical activity, and related interests and preferences. We want to emphasize that you are free to choose not to answer any question that you don’t wish to. As well, you are free to leave at any time [tonight/this afternoon/this morning], should you not be feeling well, or should the topic become too uncomfortable for you to stay.
Before we proceed, I would like to go over some ground rules

- We would like to ask you to do your best to give your name before you speak each time. This is a great help with transcribing the recordings. You may also hear me say your name, as in “Thank you, Karen,” after you speak. That is also a big help to the transcriptionist. As you could imagine, it can be difficult to tell everyone apart when you weren’t actually at the meeting!

- While we understand that you will realize you have an important point to add to the conversation at certain times, please do your best not to interrupt anyone while they are speaking.

- I want to emphasize that we are interested in hearing everyone’s opinions...no one opinion is more “right” or more valuable than anyone else’s, so it may help to keep in mind that it is definitely okay if we all don’t agree, but please show respect to others’ opinions.

- Finally, it is important that this focus group discussion be kept confidential. We all need to agree that we will not tell others what was said here, in order to protect the confidentiality of your fellow participants. Do you all agree to keep [tonight’s/this afternoon’s/this morning’s] discussion confidential?

[Interviewer scans the room for verbal and non-verbal signs of agreement.]

Ok, that’s great. Thanks everyone. We’re about to move on to the questions. I am going to begin the recording now... [Researcher starts the recording equipment and asks a couple of participants in different locations in the room to say something to test the reception on the equipment.]

1. To begin, I would like to know how you define or describe leisure-time physical activity. What does the term mean to you?

2. Would you describe yourself as physically active? Why or why not

   Possible probes:
   - Typical daily activities (e.g., at work, home, community and for leisure)
   - Important activities
   - LTPA-related interests and preferences

3. How does your participation in physical activity affect your overall health and well-being?
   Possible probes:
   - How do you feel when you engage in physical activity?
4. Next, I want you to reflect on your own life and what has encouraged or motivated you to be physically active. In other words, what motivates you engage in LTPA? Let’s create a list.
   Possible motivation probes:
   • Health
   • Appearance
   • Enjoyment
   • Physical and psychological well-being
   • Being with others

5. Thank you for that list. Based on your knowledge about LTPA, and your previous experiences, what are some of your most significant challenges or issues related to engaging in LTPA? In other words, what discourages you from being physically active? Let’s create another list.
   Possible challenges/issue probes:
   • Weather (cold/heat/rain)
   • Health-related factors
   • Safety concerns in the community
   • Physical environment (sidewalks/lightning)
   • Fear of falls or injuries
   • Lack of interest/motivation
   • Lack of someone to do it with
   • Lack of time
   • Lack of financial resources to engage in physical activity of choice

6. What steps have you taken to manage or reduce these issues in the past?
   Possible probes
   • Seeking and obtaining information about support resources and services
   • Incorporating physical activity into everyday routines (e.g., walking to the photocopier at work, taking stairs instead of elevators)

   *Next, I would like to switch to talk about programs, resources and services to support your engagement in leisure-time physical activity*

7. What do you think about the opportunities available in your community for you to engage in LTPA?
   Possible probes
• Availability of support resources and services
• Are these resources and services adequate to suit your needs
• Access to information about the support resources available
• Affordability of these resources

8. What are your feelings about having family or friends who live nearby to engage in leisure-time physical activity together with you?
   Possible probes
   • The types of shared activities you can engage in,
   • The value of having the support of family and friends to engage in leisure-time physical activity

9. Finally, if you could imagine an ideal program that would support you to engage in leisure-time physical activity, what would it look like?
   Possible probes
   • A program that you could do alone or with a partner?
   • A program that would be delivered at home or at a leisure center (how far would you be willing to travel)
   • How many sessions?
   • What type of content

OK. I see that our time is almost at an end [tonight/this afternoon/this morning]. Just before we wrap up, is there anything that we have missed or that you have not had a chance to say on this topic?

[Researcher facilitates comments and then provides a brief summary of the highlights of the discussion until the end of the allotted time.]

We would both like to thank you again for taking the time out of your busy schedules to share your thoughts and feelings with us about this challenging topic. We look forward to keeping those of you interested up to date on the findings from the focus groups. Please don’t hesitate to let us know if you have any questions or concerns at all, either by phone or email.

We will be here for a short time while we tidy and pack up. Please feel free to speak with us afterwards if you have any comments or questions, too.

Many thanks
Appendix D: Manuscript 1 demographics and other data collection
questionnaire

Focus Group Participant Demographics and Other Data Collection Surveys (For People with MS)

Thank you for agreeing to participate in our study. The information on this survey will be used to
help us describe the people who participated in our focus groups. Please answer each question
with the answer that fits you the best.

First, we would like to ask you some questions about your background:

1. Are you:
   □ Male (0)
   □ Female (1)

2. What is your birth date? Day_____ Month_____ Year_____

3. What is your current marital status? (Check one)
   □ Married or Partnership (0)
   □ Single (never married) (1)
   □ Separated or Divorced (2)
   □ Widow or Widower (3)

4. Who else lives with you? (Check all that apply)
   □ No one (I live alone) (0)
   □ Spouse or partner (1)
   □ Parent/s (2)
   □ Sibling/s (3)
   □ Child/Children (4)
   □ Other (please specify) (5) _______________________
   □ I’d rather not say (777)
5. What is the highest level schooling that you completed?

☐ No schooling (0)
☐ 8th grade or less (1)
☐ Grades 9 – 11 (2)
☐ High school (3)
☐ Technical or trade school (4)
☐ College (5)
☐ Bachelor’s degree (6)
☐ Master’s degree (7)
☐ Doctorate degree (PhD, JD, EdD, MD) (8)
☐ I’d rather not say (777)

6. What is your current employment status? (Check one)

☐ Full time (40 hours or more per week) (0)
☐ Part time (20 to 39 hours per week) (1)
☐ Part time (1 to 19 hours per week) (2)
☐ Unemployed (unable to find work) (3)
☐ Unemployed (chose not to work) (4)
☐ Unemployed (unable to work – disability) (5)
☐ Homemaker; do not work outside the home (6)
☐ Retired (7)
☐ Student (8)
☐ I’d rather not say (777)

We would now like to ask you some questions about your overall health, and specifically about your MS and your symptoms:

7. What type of MS do you have? (Check one)

☐ Relapsing/Remitting (0)
☐ Primary Progressive (1)
☐ Secondary Progressive (2)
☐ Progressive/Relapsing (3)
☐ Not sure (888)
8. What year did your symptoms first start? __________

9. What year were you first diagnosed with MS? __________

10. Would you say that your MS is within the last year:

☐ Stable (0)
☐ Improving (1)
☐ Deteriorating (2)
☐ Variable (3)
☐ Don't know (888)

11. Some people with MS have other health conditions besides MS. Has your doctor ever told you that you have...

a. Hypertension (i.e., high blood pressure) ☐ YES (1) ☐ NO (0)

b. Heart disease ☐ YES (1) ☐ NO (0)

c. Diabetes ☐ YES (1) ☐ NO (0)

d. Hyperlipidemia ☐ YES (1) ☐ NO (0)

e. Chronic Lung Disease (e.g., asthma, COPD) ☐ YES (1) ☐ NO (0)

f. Depression ☐ YES (1) ☐ NO (0)

g. Anxiety ☐ YES (1) ☐ NO (0)

h. Visual loss ☐ YES (1) ☐ NO (0)

i. Hearing loss ☐ YES (1) ☐ NO (0)

12. In general, would you say your health is (check one):

☐ Excellent (4)
☐ Very Good (3)
☐ Good (3)
☐ Fair (1)
☐ Poor (0)
Next, we would like to ask you about your ability to get around:

13. From the list of statements that follows, please choose the one that best describes your own situation. The statements focus mainly on how well you walk. Not everyone will find a description that reflects their situation exactly, but please identify the one that comes closest for you.

☐ 0 – You may have some mild symptoms, mostly sensory due to MS but they do not limit your activity. If you do have an attack, you return to normal when the MS attack (relapse or exacerbation) has passed.

☐ 1 - You have some noticeable symptoms from your MS but they are minor and have only a small effect on your lifestyle.

☐ 2 - You don’t have any limitations in your walking ability. However, you do have significant problems due to MS that limit daily activities in other ways.

☐ 3 - MS interferes with your activities, especially your walking. You can work a full day, but athletic or physically demanding activities are more difficult than they used to be. You usually don’t need a cane or other assistance to walk, but you might need some assistance during a MS attack (relapse or exacerbation).

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

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

☐ 6 - To walk as far as 25 feet you must have 2 canes or crutches or a walker. You may use a scooter or wheelchair for longer distances.

☐ 7 - Your main form of mobility is a wheelchair. You may be able to stand and/or take one or two steps, but you can’t walk 25 feet, even with crutches or a walker.

☐ 8 – You are unable to sit in a wheelchair for more than one hour.

14. These questions ask about limitations to your walking due to MS during the past 2 weeks. For each statement, please circle (or click on) the one number that best describes your degree of limitation. Please answer all questions, even if some seem rather similar to others, or seem irrelevant to you.

If you cannot walk at all, please check this box: ☐

<table>
<thead>
<tr>
<th>In the past two weeks, how much has your MS ...</th>
<th>Not at all</th>
<th>A little</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Limited your ability to walk?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Limited your ability to run?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. Limited your ability to climb up and down stairs?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. Made standing when doing things more difficult?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. Limited your balance when standing or walking?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. Limited how far you are able to walk?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. Increased the effort needed for you to walk?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. Made it necessary for you to use support when walking indoors (e.g., holding on to furniture, using a stick, etc.)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>In the past two weeks, how much has your MS ...</td>
<td>Not at all</td>
<td>A little</td>
<td>Moderately</td>
<td>Quite a bit</td>
<td>Extremely</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>------------</td>
<td>----------</td>
<td>------------</td>
<td>-------------</td>
<td>-----------</td>
</tr>
<tr>
<td>9. Made it necessary for you to use support when walking outdoors (e.g., using a stick, a frame, etc.)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. Slowed down your walking?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. Affected how smoothly you walk?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. Made you concentrate on your walking?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

15. How often do you use the following mobility aids – never, sometimes or always?

<table>
<thead>
<tr>
<th>Aid</th>
<th>Never</th>
<th>Sometimes</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cane</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Crutches</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Walker</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Manual wheelchair</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Power wheelchair</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Scooter</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

16. Have you fallen to the ground in the past 6 months?
- □ No (0)
- □ Not sure (1)
- □ Yes (2)
17. Are you concerned about falling?
   - No (0)
   - Not sure (1)
   - Yes (2)

18. Are there things that you avoid doing because you are concerned about falling?
   - No (0)
   - Yes (1)
   - N/A (999)

19. What are the things that you avoid doing because of your concern about falling?

The questions that follow are related to your symptoms and how they impact your daily life.

20. There is a list below of common MS symptoms. Please choose the column which is the most accurate description of how much each of them interferes with your typical daily activities – is the symptom not a problem for you, does it interfere a little bit, or does it interfere a great deal?

<table>
<thead>
<tr>
<th></th>
<th>Not a problem for you</th>
<th>Interferes a little bit</th>
<th>Interferes a great deal</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>888</td>
</tr>
<tr>
<td>Problems with balance or</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>888</td>
</tr>
<tr>
<td>mobility</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>888</td>
</tr>
<tr>
<td>Spasticity</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>888</td>
</tr>
<tr>
<td>Loss of coordination</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>888</td>
</tr>
<tr>
<td>Poor concentration,</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>888</td>
</tr>
<tr>
<td>forgetfulness</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
21. Thinking about your symptoms and your ability to do everyday activities, how do you think you manage now compared to one year ago?

☐ About the same (1)
☐ Worse (2)
☐ Better (3)
☐ Don’t know (888)

This is the end of the survey. Thank you very much for your time.
Focus Group Participant Demographics and Other Data Collection Surveys (For Friends or Family Members of People with MS)

Thank you for agreeing to participate in our study. The information on this form will be used to help us describe the people who participated in our focus groups. Please answer each question with the answer that fits you the best. First, we would like to ask you some questions about your background:

1. Are you:
   - □ Male (0)
   - □ Female (1)

2. What is your birth date? Day____ Month____ Year____

3. What is your current marital status: (Check one)
   - □ Married or Partnership (0)
   - □ Single (never married) (1)
   - □ Separated or Divorced (2)
   - □ Widow or Widower (3)

4. What is your relationship with the person who has MS?
   - You are his or her:
     - □ Spouse or partner (0)
     - □ Parent (1)
     - □ Child (2)
     - □ Sibling/s (3)
     - □ Uncle/Aunt (4)
     - □ Nephew/Niece (5)
     - □ Other (6) (please specify)__________________
5. Do you live with the person who has MS?

☐ Yes (1)
☐ No (0)

6. Who else lives with you (besides the person with MS)?

☐ No one (I live alone) (0)
☐ Spouse or partner (1)
☐ Parent/s (2)
☐ Sibling/s (3)
☐ Child/Children (4)
☐ Other (please specify) (5) ________________
☐ I’d rather not say (777)

7. How many years of schooling did you complete?

☐ No schooling (0)
☐ 8th grade or less (1)
☐ Grades 9 – 11 (2)
☐ High school (3)
☐ Technical or trade school (4)
☐ College (5)
☐ Bachelor’s degree (6)
☐ Master’s degree (7)
☐ Doctorate degree (PhD, JD, EdD, MD) (8)
☐ I’d rather not say (777)

8. What is your current employment status? (Check one)

☐ Not working – full time caregiver (0)
☐ Full time (40 hours or more per week) (1)
☐ Part time (20 to 39 hours per week) (2)
Part time (1 to 19 hours per week) (3)
Unemployed (unable to find work) (4)
Unemployed (chose not to work) (5)
Unemployed (unable to work – disability) (6)
Homemaker; do not work outside the home (7)
Retired (8)
Student (9)
I’d rather not say (777)

9. In general, would you say your health is (check one):

Excellent (4)
Very Good (3)
Good (2)
Fair (1)
Poor (0)

Now, we would like to ask you some questions about the person with MS and his or her MS, as well as the type of assistance or support you provide. Assistance or support refers to any physical, emotional, or informational help you provide the person with MS:

10. How many years have you known the person with MS?

__________ years

11. Are you currently providing the person with MS with assistance or support with daily activities?

☐ No (0)
☐ Don’t know (1)
☐ Yes (2)

If yes, how long have you been providing the person with MS with assistance or support because of his/her MS symptoms?

__________ years
12. The symptoms of MS can make it difficult for a person to do everyday activities. We are interested in which of these activities you typically provide the person with MS assistance and support to do. Please select the best option (no, sometimes, or regularly) for each activity:

<table>
<thead>
<tr>
<th>Do you ever help the person with MS to:</th>
<th>0 = no</th>
<th>1 = sometimes</th>
<th>2 = regularly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Move around inside the house?</td>
<td>0 = no</td>
<td>1 = sometimes</td>
<td>2 = regularly</td>
</tr>
<tr>
<td>Go up and down a flight of stairs?</td>
<td>0 = no</td>
<td>1 = sometimes</td>
<td>2 = regularly</td>
</tr>
<tr>
<td>Get in and out of bed?</td>
<td>0 = no</td>
<td>1 = sometimes</td>
<td>2 = regularly</td>
</tr>
<tr>
<td>Get in and out of the shower or tub?</td>
<td>0 = no</td>
<td>1 = sometimes</td>
<td>2 = regularly</td>
</tr>
<tr>
<td>Get dressed?</td>
<td>0 = no</td>
<td>1 = sometimes</td>
<td>2 = regularly</td>
</tr>
<tr>
<td>Manage his/her bladder?</td>
<td>0 = no</td>
<td>1 = sometimes</td>
<td>2 = regularly</td>
</tr>
<tr>
<td>Prepare a hot meal?</td>
<td>0 = no</td>
<td>1 = sometimes</td>
<td>2 = regularly</td>
</tr>
<tr>
<td>Provide transportation?</td>
<td>0 = no</td>
<td>1 = sometimes</td>
<td>2 = regularly</td>
</tr>
</tbody>
</table>

13. When we experience stress in our lives we usually try to manage it by trying out different ways of “coping”. Sometimes our attempts are successful in helping us solve a problem or feel better, and other times they are not. Below is a list of things that people have reported they may do when confronted with problems related to caring for someone with MS. Please indicate how often you have tried each of the coping strategies in dealing with caregiving in general. There are no “right” or “wrong answers. Please substitute [the person with MS] for the name of the person with MS whom you care for and/or support.
<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>Does not Apply/never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I talk issues through with [the person with MS] in an attempt to solve the problems</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>I offer [the person with MS] physical assistance</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>I ignore the problem or pretend it doesn’t exist</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td>I look at the positives of the situation</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>I talk to others about the problem</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6</td>
<td>I turn to work or other substitute activities such as gardening, hobbies or sport, to take my mind off the problem</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7</td>
<td>I accept that this is how it is</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8</td>
<td>I blame myself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9</td>
<td>I purchase assistive equipment such as wheelchair, incontinence aids or computer to assist [the person with MS]</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10</td>
<td>I keep myself busy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11</td>
<td>I try to point out the positives to [the person with MS]</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12</td>
<td>I yell or shout at [the person with MS]</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Description</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>---</td>
<td>----------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>13</td>
<td>I keep out of [the person with MS]’s way when he/she is in a bad mood.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>I seek assistance from others, for example, employ people to do the housework or ask friends to help out.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>I tell [the person with MS] that the problem is all their fault.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>I arrange my schedule so I can be with [the person with MS] when needed.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>I wish the problem would go away</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>I seek information about the problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>I keep my problems to myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>I utilize respite services</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>I try to improve our financial situation, for example, work more hours, budget money</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>I try to snap [the person with MS] out of it</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>I take time for myself/spend time away from [the person with MS]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>I closely monitor [the person with MS]</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I tell [the person with MS] what to do</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>---</td>
<td>-------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>25</td>
<td>I participate in activities we can do together in order to develop our relationship.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>26</td>
<td>I criticize [the person with MS]</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>27</td>
<td>I try to keep aware of [the person with MS]'s needs and endeavor to meet these, for example, I know when to slow down or take a rest</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>28</td>
<td>I offer emotional support to [the person with MS]</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>29</td>
<td>I nag [the person with MS]</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>30</td>
<td>I laugh and try to find humor in the situation</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>31</td>
<td>I talk to health care professionals about the problem, for example, GP, specialist or psychologist</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>32</td>
<td>I drink or smoke more</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>33</td>
<td>I try to solve the problem on my own.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>34</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Coping with MS Caregiving Inventory (CMSC); Pakkenhau K. 2002 Development of a Measure of Coping with Multiple Sclerosis Caregiving*  
*Psychology & Health, 17(1), 97-118, DOI: 10.1191/0269900502ph10557*

*This is the end of the survey. Thank you very much for your time.*
Appendix E: Manuscript 2 letter of information and consent form

Letter of Information

Project title: A needs assessment to inform the development of a dyadic physical activity program for people with MS who have moderate to severe disability and their caregivers

Researchers:
Ms. Afolasade Farotimi, School of Rehabilitation Therapy, Queen’s University
Dr. Marcia Finlayson, School of Rehabilitation Therapy, Queen’s University
Dr. Amy Latimer, School of Kinesiology & Health Studies, Queen’s University
Dr. Trisha Parsons, School of Rehabilitation Therapy, Queen’s University

What is this study about?
Regular engagement in leisure-time physical activity is beneficial for all people and for people with MS in particular. However, many people with MS who have moderate to severe disability may find it challenging to engage in leisure-time physical activity. Also, caregivers may have limited time and opportunity to engage in leisure-time physical activity due to their caregiving responsibilities. The overall goal of this study is to determine whether there is a need for a program that supports people with MS who have moderate to severe disability and their caregivers to engage in leisure-time physical activity together.

We are inviting you to participate in a study assessing the level of physical activity and the pattern of activity in people with MS who have moderate to severe disability and their caregivers.

What procedures are involved?
If you agree to be in this study, we would ask you to:

- Wear a motion sensor device called an accelerometer on your waist to track your physical activity. The accelerometer will be worn daily during waking hours except when showering, bathing or swimming for a 7-day monitoring period.
- Record the time the accelerometer is put on and taken off and the specific activities carried out during the time the accelerometer is worn.
- Complete a self-reported questionnaire on the types of physical activities you engage in during a typical week.

What are the potential risks and discomforts?
There are no identifiable risks associated with participating in this study. However, you may experience mild physical discomfort associated with engaging in physical activity if
you have been previously inactive. You may also experience mild physical injury if you become competitive with your scores and end up overdoing an activity.

**Are there benefits to taking part in the research?**
There are no direct benefits to you from taking part in this research. Your participation in this study would help the researchers determine the relationship between the level and pattern of physical activity in people with MS who have moderate to severe disability and their caregivers. Your participation will also provide information that may inform the development of programs to support regular engagement in leisure-time physical activity for people with MS and their caregivers.

**Is my participation voluntary?**
Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the Queen’s University or any organization through which you heard about this study. If you decide to participate, you are free to withdraw at any time without affecting those relationships.

**What will happen to the information collected?**
All the study information collected from you will be stored in a safe and locked location in the Multiple Sclerosis Rehabilitation Research Suite of Dr. Marcia Finlayson in Botterell Hall at Queen’s University. It will be kept for 10 years after it is analyzed and published. Your name will not appear on any documents related to your participation in this study. We will identify you by a code in order to maintain your confidentiality.

**Will I be compensated for my participation?**
You will not receive any payment for your participation in this study.

**What if I have concerns?**
Any questions about study participation may be directed to Ms. Farotimi at the MS Rehabilitation Research Suite on 1-855-533-3407 toll-free. If you have any concerns about your rights as a research participant please contact Dr. Albert Clark – Chair of the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at 613-533-6081.

*Your interest in participating in this research study is greatly appreciated*
*This study has been granted clearance according to the recommended principles of Canadian ethics guidelines, and Queen’s policies.*
Consent Form

“A needs assessment to inform the development of a dyadic physical activity program for people with MS who have moderate to severe disability and their caregivers”

1. I have read the Letter of Information and have had any questions answered to my satisfaction.

2. I understand that I will be participating in the study called “A needs assessment to inform the development of a dyadic physical activity program for people with MS who have moderate to severe disability and their caregivers.” I understand that this means that I will be asked to wear a lightweight motion sensor device called an accelerometer on my waist during daily waking hours for a period of 7 days, record when the accelerometer is put on and taken off and the specific activities I carried out while wearing the accelerometer. In addition, I will complete a self-report questionnaire on my physical activity in a typical week.

3. I understand that my participation in this study is voluntary and I may withdraw at any time. I understand that every effort will be made to maintain the confidentiality of the data now and in the future. Only the members of the research team conducting the study will have access to these data. The findings may be published in professional journals or presented at scientific conferences, but any such papers or presentations will be of general findings and will never breach individual confidentiality. Should I be interested, I am entitled to a copy of the findings.

4. I am aware that if I have any questions, concerns, or complaints, I may contact Ms. Farotimi at the MS Rehabilitation Research Suite on 1-855-533-3407 toll-free.

5. If I have any concerns about my rights as a research participant, I can contact Dr. Albert Clark – Chair of the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at 613-533-6081.
This study has been granted clearance according to the recommended principles of Canadian ethics guidelines, and Queen's policies.

Your signature below indicates that you have read this Letter of Information and have had any questions answered to your satisfaction. Please keep a copy of this letter for your records.

I have read the above statements and freely consent to participate in this research:

Name: ________________________  Date: ________________________

Signature: ________________________

I am willing to be contacted for future MS-related studies conducted by members of this research team:

□ Yes  □ No

If yes to the above, please write your preferred contact address (email/regular mail, phone number) below:

________________________________________________________________________________________

Name of Witness/Interviewer: ________________________

Signature of the Witness/Interviewer: ________________________
Appendix F: Manuscript 2 instructions for wearing the accelerometer

How Long You Should Wear Your Accelerometer

When you send your accelerometer back, we will see how many hours you wore it each day. If we see that you didn't wear it for 7 days, for at least 12 hours per day, we may have to send it back for you to wear again.

Check out the graphs below to see some examples of how you should and shouldn't wear the accelerometer.

This person did a great job of wearing their accelerometer!
As you can see on the graph, they put it on when they woke up at about 6:00 in the morning, and kept it on until about 10:30 at night.

This person would have to wear the accelerometer again.
They put it on when they woke up at about 7:00 in the morning, but took it off at about 2:30 in the afternoon.

If you have any questions about your accelerometer, please contact the MS Rehabilitation Research Suite on 1-855-533-3407 toll-free.
Appendix G: Manuscript 2 physical activity log

Daily Activity Log for People with MS

Please fill the time you put on and take off the accelerometer each day. Also write down your daily activities during wear time and the approximate times spent doing each activity.

<table>
<thead>
<tr>
<th>Day &amp; Date</th>
<th>Time on</th>
<th>Time off</th>
<th>Activities lasting at least 10 min in duration during wear time (e.g., walking, gardening, vacuuming, personal care, transportation etc.)</th>
<th>Time (in minutes) spent doing each activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day &amp; Date</td>
<td>Time on</td>
<td>Time off</td>
<td>Activities lasting at least 10 min in duration during wear time (e.g., walking, gardening, vacuuming, personal care, transportation etc.)</td>
<td>Time (in minutes) spent doing each activity</td>
</tr>
<tr>
<td>------------</td>
<td>---------</td>
<td>----------</td>
<td>-----------------------------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------</td>
</tr>
<tr>
<td>Day 2</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Date:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day &amp; Date</td>
<td>Time on</td>
<td>Time off</td>
<td>Activities lasting at least 10 min in duration during wear time (e.g., walking, gardening, vacuuming, personal care, transportation etc.)</td>
<td>Time (in minutes) spent doing each activity</td>
</tr>
<tr>
<td>------------</td>
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<td>---------------------------------------------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------</td>
</tr>
<tr>
<td>Day 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Day & Date | Time on | Time off | Activities lasting at least 10 min in duration during wear time (e.g., walking, gardening, vacuuming, personal care, transportation etc.) | Time (in minutes) spent doing each activity
---|---|---|---|---
Day 4 | Date: | | | |

ID Number: ____________

218
<table>
<thead>
<tr>
<th>Day &amp; Date</th>
<th>Time on</th>
<th>Time off</th>
<th>Activities lasting at least 10 min in duration during wear time (e.g., walking, gardening, vacuuming, personal care, transportation etc.)</th>
<th>Time (in minutes) spent doing each activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day &amp; Date</td>
<td>Time on</td>
<td>Time off</td>
<td>Activities lasting at least 10 min in duration during wear time (e.g., walking, gardening, vacuuming, personal care, transportation etc.)</td>
<td>Time (in minutes) spent doing each activity</td>
</tr>
<tr>
<td>------------</td>
<td>---------</td>
<td>----------</td>
<td>----------------------------------------------------------------------------------------------------------------</td>
<td>--------------------------------------------</td>
</tr>
<tr>
<td>Day 6</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day &amp; Date</td>
<td>Time on</td>
<td>Time off</td>
<td>Activities lasting at least 10 min in duration during wear time (e.g., walking, gardening, vacuuming, personal care, transportation etc.)</td>
<td>Time (in minutes) spent doing each activity</td>
</tr>
<tr>
<td>-----------</td>
<td>---------</td>
<td>----------</td>
<td>--------------------------------------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------</td>
</tr>
<tr>
<td>Day 7</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix H: Manuscript 3 ethics approval

QUEEN’S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING HOSPITALS
RESEARCH ETHICS BOARD (HSREB)

HSREB Amendment Acknowledgment/Ethics Clearance

April 25, 2016

Ms. Afolasade Fakolade
School of Rehabilitation Therapy
Louise D. Acton Building

ROMEO/TRAQ: #6014723
Department Code: REH 610-15
Study Title: A needs assessment to inform the development of a dyadic physical activity program for people with multiple sclerosis who have moderate to severe disability and their caregivers
Review Type: Delegated
Date Ethics Clearance Issued: April 25, 2016

Dear Ms. Fakolade,

The Queen’s University Health Sciences & Affiliated Teaching Hospitals Research Ethics Board (HSREB) has reviewed the amendment application and granted ethics clearance/acknowledgement for the following:

- Aim 3 – Needs Assessment Study Survey
- Recruitment Flyer
- Concerns Report Survey – Participants with MS
- Concerns Report Survey – Family Caregivers

Yours sincerely,

[Signature]

Chair, Health Sciences Research Ethics Board

The HSREB operates in compliance with, and is constituted in accordance with, the requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations; Canadian General Standards Board, and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is qualified through the CTO REB Qualification Program and is registered with the U.S. Department of Health and Human Services (DHHS) Office for Human Research Protection (OHRP). Federalwide Assurance Number: FWA#0000184, IRB#00001173

HSREB members involved in the research project do not participate in the review, discussion or decision.
Appendix I: Manuscript 3 physical activity concerns report survey for people with MS

Researchers from Queen's University are conducting a study about joint participation of people with MS and their family caregivers in leisure-time physical activity. We are inviting you to participate in this survey to identify concerns and priorities for physical activity participation among people with MS who have moderate to severe disability and their family caregivers. By participating in this study, you will be providing information that may inform the development of programs to support joint participation of people with moderate to severe MS and their family caregivers in leisure-time physical activity. If you agree to participate, we ask that you complete this web-based survey that will take about 20-25 minutes to complete.

You can choose not to answer any questions that you do not want to answer. If you do not wish to respond to particular questions, please skip over them. You may complete the survey in multiple sessions. You may begin the survey on one device and continue where you left off on another device. Use the buttons at the bottom of the survey to navigate through the survey. Your participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with Queen's University or any organization through which you heard about this study. If you decide to participate, you are free to withdraw by signing off at any time without affecting those relationships.

Please be assured that your responses will be kept confidential. When the results of the research are published or discussed at conferences, no information will be included that would reveal your identity. This study has been granted clearance by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board according to the recommended principles of Canadian ethics guidelines and Queen's policies; feel free to contact them at 1-844-535-2988 if you have any concerns. Please direct any questions about the survey to a.farotimi@queensu.ca or call 1-855-533-3407 toll-free.
Consent Form

1. I understand the purpose of the study.

2. I understand that my participation is voluntary and I may withdraw at any time.

3. I understand that every effort will be made to maintain the confidentiality of the data now and in the future.

4. I am aware that I may direct any questions about the survey to a.farotimi@queensu.ca or call 1-855-533-3407 toll-free.

5. If I have any concerns about my rights as a research participant, I can contact the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at 1-844-535-2988.

☐ I have read the above statements and freely consent to participate in this research

Making sure you are eligible to participate in the survey

Please answer ALL of the following questions to determine if you are eligible to participate in the survey

1. Are you 18 years of age or older?
   - Yes
   - No

2. Have you been diagnosed with MS?
   - Yes
   - No

3. Do you experience any limitation in your walking ability or daily activities due to MS?
   *Limitation in walking ability or daily activities means that you may use a cane, crutch(es), scooter, wheelchair or some other form of support (e.g. touching a wall or leaning on someone's arm) sometimes or all of the time*
   - Yes
   - No

4. Are you able to complete the survey in English?
   - Yes
   - No
Thank you for your interest in participating in this survey. Unfortunately, you do not meet the eligibility criteria for the study. We are currently looking for individuals who: are 18 years or older, have been diagnosed with MS, and have limitation in walking ability or daily activities due to MS. If you would like more information about the study, please email a.farotimi@queensu.ca or call 1-855-533-3407 toll-free.

You meet all of the criteria for participating in the study. If you are still willing and able to participate, please click the "Next" button (below) to begin your survey.

Thank you for agreeing to participate in this survey. We appreciate your time and cooperation. Please read and answer each question to the best of your ability. There are no right or wrong answers. All your answers are completely confidential.

PART 1: PHYSICAL ACTIVITY PARTICIPATION

Physical activity is any body movement that works your muscles and requires more energy than resting. Walking, gardening, dancing, swimming, and yoga are a few examples of physical activity. The first group of questions will ask you about the time you spent being physically active in the past week. Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

1a. Think about all the vigorous activities that you did in the past week. Vigorous activity includes any planned or incidental activity that causes you to sweat and be out of breath or during which you could not say more than a few words without pausing for a breath. Think only about those physical activities that you did for at least 10 minutes at a time.

How many days during the past week did you do vigorous physical activity? How many minutes on each occasion?
- 0
- 1
- 2
- 3
- 4
- 5
- 6
1b. Now think about all the moderate intensity activities that you did in the past 1-week. Moderate intensity activity includes any planned or incidental activity that causes you to sweat a little and to breathe harder than normal or during which you could talk but not sing. Think only about those activities that you did for at least 10 minutes at a time.

How many days during the past 1-week did you do moderate intensity physical activity?
- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7

How many minutes on each occasion?

1c. Now think about the time you spent walking in the past 1-week. This includes at work and at home, walking to travel from place to place, and any other walking that you have done solely for recreation, sport, exercise, or leisure.

How many days during the past 1-week did you walk for at least 10 minutes at a time?
- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7

How many minutes on each occasion?

1d. Think about the time you spent sitting on weekdays during the past 1-week. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.

How many minutes did you spend sitting on each day?
2. Please list the types of activities you participated in during the past one week

<table>
<thead>
<tr>
<th>Type of activity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
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</tr>
</tbody>
</table>

3. Would you say that you are physically more active, less active or about as active as other persons your age in the general population?
   - More active
   - Less active
   - About as active
   - Other, please specify... ______________________

PART 2: COMMUNITY RESOURCES

Community resources are the people, places, programs and services that members of a given community can turn to for tools or assistance to support participation in physical activity. The next group of questions asks about community resources you may have used in the past year to support your participation in physical activity.

1. Which of the following community resources have you used to support your participation in physical activity in the past year? (Check ALL that apply)
   - Programs that are customized and flexible in presentation and delivery (e.g. face to face or over the internet, individual or group-based setting etc.)
   - Programs that provide opportunities to learn about options for incorporating physical activity in daily life
   - Programs that target the mind and body
Programs that support joint participation of people with MS and their family caregivers in physical activity (i.e. both groups can benefit from and enjoy the program)

Programs that are held in accessible locations (e.g. accessible parking, equipment, bathrooms, lockers etc.)

Program that have facilitators who have adequate MS specific knowledge and training

Programs that have affordable total cost of participation (e.g. parking, membership fees etc.)

Programs that provide people with MS and their family caregivers with the necessary skills to deal with disease-related problems

Programs that increase confidence (self-efficacy) to deal with disease-related problems among people with MS and their family caregivers

Programs that include a wide variety of relevant options for physical activity participation in the same location

Information about available resources to support physical activity participation (e.g. publicity and advertisement of programs, information on fee assistance opportunities etc.)

Accessible, reliable and safe bus routes to important places such as community recreation centers, shopping areas etc.

Walking and biking trails that form a viable transportation option to and from activities

Communities differ in the kinds of resources that are available to support physical activity participation. The following group of questions asks about how important these resources are to you versus how satisfied you are personally about the availability of these resources in your community:

2. Please rate how important these resources are to you versus how satisfied you are personally about the availability of these resources in your community

Importance vs. Satisfaction

<table>
<thead>
<tr>
<th>Programs that are customized and flexible in presentation and delivery (e.g. face to face or over the internet, individual or group-based setting etc.)</th>
<th>Importance</th>
<th>Satisfaction</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>o Very</td>
<td>o Very</td>
</tr>
<tr>
<td></td>
<td>o Important</td>
<td>o Satisfied</td>
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<tr>
<td></td>
<td>o Important</td>
<td>o Satisfied</td>
</tr>
<tr>
<td></td>
<td>o Neutral</td>
<td>o Neutral</td>
</tr>
<tr>
<td></td>
<td>o Somewhat</td>
<td>o Dissatisfied</td>
</tr>
<tr>
<td></td>
<td>Important</td>
<td>o Very</td>
</tr>
<tr>
<td></td>
<td>Unimportant</td>
<td>o Dissatisfied</td>
</tr>
</tbody>
</table>
Programs that provide opportunities to learn about options for incorporating physical activity in daily life

Programs that target the mind and body

Programs that support joint participation of people with MS and their family caregivers in physical activity (i.e. both groups can benefit from and enjoy the program)

Programs that are held in accessible locations (e.g. accessible parking, equipment, bathrooms, lockers etc.)

Program that have facilitators who have adequate MS specific knowledge and training
Programs that have affordable total cost of participation (e.g. parking, membership fees etc.)

- Somewhat Important
- Unimportant
- Very Important
- Very Unimportant
- Very

Programs that provide people with MS and their family caregivers with the necessary skills to deal with disease-related problems

- Very Important
- Important
- Neutral
- Somewhat Important
- Unimportant
- Very Important
- Satisfied
- Satisfied
- Neutral
- Neutral
- Dissatisfied
- Very
- Very
- Dissatisfied

Programs that increase confidence (self-efficacy) to deal with disease-related problems among people with MS and their family caregivers

- Very Important
- Important
- Neutral
- Somewhat Important
- Unimportant
- Very Important
- Satisfied
- Satisfied
- Neutral
- Neutral
- Dissatisfied
- Very
- Very
- Dissatisfied

Availability of a wide variety of relevant options for physical activity participation in the same location

- Very Important
- Important
- Neutral
- Somewhat Important
- Unimportant
- Very Important
- Satisfied
- Satisfied
- Neutral
- Neutral
- Dissatisfied
- Very
- Very
- Dissatisfied

Information about available resources to support physical activity participation is easy to find (e.g. Satisfied
publicity and advertisement of programs, information on fee assistance opportunities etc.)

Accessible, reliable and safe bus routes are available to important places such as community recreation centers, shopping areas etc.

Walking and biking trails connect to form a viable transportation option to and from activities

3a. Are there any other resources that can support your participation in physical activity that you would like to have available in your community?

○ Yes
○ No

3b. Please list the resources

PART 3: BARRIERS TO PHYSICAL ACTIVITY PARTICIPATION

The next group of questions asks about barriers to your participation in physical activity.

1. Thinking about sole-participation (i.e. you alone) and co-participation (i.e. with a supportive family caregiver) in physical activity, please indicate how much of a barrier each of the following items is to you personally when you participate in physical activity alone versus with a supportive family caregiver

Sole-participation  Co-participation (with 
(you alone) a family caregiver)
<table>
<thead>
<tr>
<th>a. Lack of motivation to initiate and maintain participation in a physical activity program</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Very small barrier</td>
</tr>
<tr>
<td>☐ Small barrier</td>
</tr>
<tr>
<td>☐ Neutral</td>
</tr>
<tr>
<td>☐ Big barrier</td>
</tr>
<tr>
<td>☐ Very big barrier</td>
</tr>
</tbody>
</table>

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<thead>
<tr>
<th>b. Lack of confidence in ability to be physically active</th>
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<tr>
<td>☐ Very small barrier</td>
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<th>c. Lack of enjoyment of physical activity</th>
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<th>d. Lack of time to participate in physical activity</th>
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e. Lack of child care/ elder care support

- Very small barrier
- Small barrier
- Neutral
- Big barrier
- Very big barrier

f. Lack of choice and control over physical activity and level of participation

- Very small barrier
- Small barrier
- Neutral
- Big barrier
- Very big barrier

g. Lack of accessible locations for physical activity (e.g. equipment, bathrooms, parking, elevators, ramps etc.)

- Very small barrier
- Small barrier
- Neutral
- Big barrier
- Very big barrier

h. Fitness level e.g. cardiovascular or strength

- Very small barrier
- Small barrier
- Neutral
- Big barrier
- Very big barrier
<table>
<thead>
<tr>
<th>i. Embarrassment about personal appearance when participating in physical activity</th>
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<tbody>
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<td>Very small barrier</td>
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<td>Small barrier</td>
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<td>Very big barrier</td>
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<th>j. Variability or unpredictability associated with MS</th>
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<td>Very small barrier</td>
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<td>Small barrier</td>
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<th>k. Energy requirement for physical activity is too high</th>
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<th>l. Total cost of participating in a physical activity program is high (e.g. parking, membership fees etc)</th>
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<td>Neutral</td>
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<td>Big barrier</td>
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<td>Very big barrier</td>
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</table>
m. Safety issues within the community (e.g. excessive crime or fear of crime in neighborhood, absence of street lighting at night, excessive car traffic etc.)

- Very small barrier
- Small barrier
- Neutral
- Big barrier
- Very big barrier

n. Bad weather (e.g. rain, snow, or excessive heat)

- Very small barrier
- Small barrier
- Neutral
- Big barrier
- Very big barrier

PART 4: DEMOGRAPHIC AND GENERAL HEALTH QUESTIONS

We would like to ask you some questions about your background:

1. Which of the following describes your gender? (Check one)
   - Male
   - Female
   - Transgender
   - Do not identify as male, female or transgender
   - I'd rather not say

2. What is your age?
   - 18-24
   - 25-34
   - 35-44
   - 45-54
   - 55-64
   - 65 or Above
   - I'd rather not say

3. What is your current marital status: (Check one)
○ Single, Never Married
○ Married
○ Living common-law
○ Separated
○ Divorced
○ Widowed
○ I'd rather not say

4. Including yourself, how many persons live in your household?
○ 1
○ 2
○ 3
○ 4
○ 5
○ 6
○ 7
○ 8
○ 9
○ 10+

5. Who else lives with you? (Check all that apply)
□ No one (I live alone)
□ Spouse
□ Common-law partner
□ Parent/s
□ Child/Children
□ Sibling/s
□ I’d rather not say
□ Other, please specify... ______________________

6. Please check the box which best describes where you live
○ Rural area
○ Small population centre, with a population of between 1,000 and 29,999
○ Medium population centre, with a population of between 30,000 and 99,999
○ Large urban population centre, consisting of a population of 100,000 and over
○ I'd rather not say
8. What is the highest level schooling that you completed?
   - No schooling
   - 8th grade or less
   - Some high school
   - High school graduation
   - Technical or trade school
   - Diploma
   - Bachelor’s degree
   - Master’s degree
   - Doctorate degree (PhD, JD, EdD, MD)
   - I’d rather not say

9. What is your current employment status? (Check one)
   - Full-Time (≥40 hours per week)
   - Part-Time (20–39 hours per week)
   - Part time (1–19 hours per week)
   - Self-employed
   - Unemployed (unable to find work)
   - Unemployed (unable to work – disability)
   - Unemployed (choose not to work)
   - Homemaker (do not work outside the home)
   - Retired
   - I’d rather not say

10. What is your total personal gross income? (Check one)
    - Less than $5,000
    - $5,000 to less than $10,000
    - $10,000 to less than $15,000
    - $15,000 to less than $20,000
    - $20,000 to less than $25,000
    - $25,000 to less than $30,000
    - $30,000 to less than $40,000
    - $40,000 to less than $50,000
    - $50,000 to less than $60,000
    - $60,000 to less than $70,000
We would now like to ask you some questions about your overall health, and specifically about your MS and your symptoms:

11. In general, would you say your health is (check one):
   - Excellent
   - Very Good
   - Good
   - Fair
   - Poor
   - I'd rather not say

12. What type of MS do you have? (Check one)
   - Relapsing/Remitting
   - Primary Progressive
   - Secondary Progressive
   - Progressive/Relapsing
   - Not sure

13. What year did your symptoms first start?
   - 2016
   - 2015
   - 2014
   - 2013
   - 2012
   - 2011
   - 2010
   - 2009
   - 2008
   - 2007
   ... 56 additional choices hidden ...
14. What year were your first diagnosed with MS?
   - 1949
   - 1948
   - 1947
   - 1946
   - 1945
   - 1944
   - 1943
   - 1942
   - 1941
   - 1940

15. Would you say that your MS is within the last year:
16. Some people with MS have other health conditions besides MS. Has your doctor ever told you have:

- Hypertension (i.e., high blood pressure)
- Hyperlipidemia (i.e., high cholesterol)
- Chronic Lung Disease (e.g., asthma, COPD)
- Depression
- Anxiety

Now, we would like to ask you about your ability to get around:

17. From the list of statements that follows, please choose the one that best describes your own situation. The statements focus mainly on how well you walk. Not everyone will find a description that reflects their situation exactly, but please identify the one that comes closest for you.

- You may have some mild symptoms, mostly sensory due to MS but they do not limit your activity.
  - If you do have an attack, you return to normal when the MS attack (relapse or exacerbation) has passed

- You have some noticeable symptoms from your MS but they are minor and have only a small effect on your lifestyle

- You don't have any limitations in your walking ability. However, you do have significant problems due to MS that limit daily activities in other ways

- MS interferes with your activities, especially your walking. You can work a full day, but athletic or physically demanding activities are more difficult than they used to be. You usually don't need a cane or other assistance to walk, but you might need some assistance during a MS attack (relapse or exacerbation)

- You use a cane or a single crutch or some other form of support (such as touching a wall or leaning on someone's arm) for walking all the time or part of the time, especially when walking outside. You think you can walk 25 feet in 20 seconds without a cane or crutch. You always need some assistance (cane or crutch) if you want to walk as far as 3 blocks
○ To walk 25 feet, you have to have a cane, crutch or someone to hold onto. You can get around the house or other buildings by holding onto furniture or touching the walls for support. You may use a scooter or wheelchair if you want to go greater distances
○ To walk as far as 25 feet you must have 2 canes or crutches or a walker. You may use a scooter or wheelchair for longer distances
○ Your main form of mobility is a wheelchair. You may be able to stand and/or take one or two steps, but you can't walk 25 feet, even with crutches or a walker
○ You are unable to sit in a wheelchair for more than one hour

18. These questions ask about limitations to your walking due to MS during the past 2 weeks. For each statement, please choose the option that best describes your degree of limitation. Please answer all questions, even if some seem rather similar to others, or seem irrelevant to you.
□ If you cannot walk at all, please check this box

In the past two weeks, how much has your MS …

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
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<tbody>
<tr>
<td>Limited your ability to walk?</td>
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<td>Limited your ability to run?</td>
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<td>Limited your ability to climb up and down stairs?</td>
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<tr>
<td>Made standing when doing things more difficult?</td>
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<td>Limited your balance when standing or walking?</td>
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<tr>
<td>Limited how far you are able to walk?</td>
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<tr>
<td>Increased the effort needed for you to walk?</td>
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<tr>
<td>Made it necessary for you to use support when walking indoors (e.g., holding onto furniture, using a stick, etc.)?</td>
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<tr>
<td>Made it necessary for you to use support when walking outdoors (e.g., using a stick, a frame, etc.)?</td>
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<tr>
<td>Slowed down your walking?</td>
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<tr>
<td>Affected how smoothly you walk?</td>
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<tr>
<td>Made you concentrate on your walking?</td>
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</table>

19. How often do you use the following mobility aids?

Never  Rarely  Sometimes  Often  Always
Cane ○ ○ ○ ○ ○ ○
Crutches ○ ○ ○ ○ ○ ○
Walker ○ ○ ○ ○ ○ ○
Manual wheelchair ○ ○ ○ ○ ○ ○
Power wheelchair ○ ○ ○ ○ ○ ○
Scooter ○ ○ ○ ○ ○ ○

This is the end of the survey. Thank you for your participation in this important research. All your answers will remain confidential and when survey results are reported, your answers will be combined with the answers of others so that you cannot be identified. The responses you provide would help the researchers understand the concerns and priorities for physical activity participation among people with MS who have moderate to severe disability and their family caregivers. Your participation will also provide information that may inform the development of programs to support regular participation in leisure-time physical activity for people with MS and their caregivers. Please click the "Survey completed, I submit my responses" button (below) to complete your survey. If your close friend or family member would like to participate, please copy and paste the link below into another browser. They will be directed to the concerns report survey for friends or family members of people with MS http://queensu.fluidsurveys.com/s/familycaregivers/
Appendix J: Manuscript 3 physical activity concerns report survey for family caregivers

Researchers from Queen's University are conducting a study about joint participation of people with MS and their family caregivers in leisure-time physical activity. We are inviting you to participate in this survey to identify concerns and priorities for physical activity participation among people with MS who have moderate to severe disability and their family caregivers. By participating in this study, you will be providing information that may inform the development of programs to support joint participation of people with moderate to severe MS and their family caregivers in leisure-time physical activity. If you agree to participate, we ask that you complete this web-based survey that will take about 20-25 minutes to complete.

You can choose not to answer any questions that you do not want to answer. If you do not wish to respond to particular questions, please skip over them. Use the buttons at the bottom of the survey to navigate through the survey. Your participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with Queen's University or any organization through which you heard about this study. If you decide to participate, you are free to withdraw by signing off at any time without affecting those relationships.

Please be assured that your responses will be kept confidential. When the results of the research are published or discussed at conferences, no information will be included that would reveal your identity. This study has been granted clearance by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board according to the recommended principles of Canadian ethics guidelines and Queen's policies; feel free to contact them at 1-844-535-2988 if you have any concerns. Please direct any questions about the survey to a.farotimi@queensu.ca or call 1-855-533-3407 toll-free.
Consent Form

1. I understand the purpose of the study.

2. I understand that my participation is voluntary and I may withdraw at any time.

3. I understand that every effort will be made to maintain the confidentiality of the data now and in the future.

4. I am aware that I may direct any questions about the survey to a.farotimi@queensu.ca or call 1-855-533-3407 toll-free.

5. If I have any concerns about my rights as a research participant, I can contact the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at 1-844-535-2988.

☐ I have read the above statements and freely consent to participate in this research.

Making sure you are eligible to participate in the survey

Please answer ALL of the following questions to determine if you are eligible to participate in the survey.

1. Are you 18 years of age or older?
   ○ Yes
   ○ No

2. Do you provide at least 45mins/day of support or assistance to a friend or family member with MS?
   Support or assistance include physical, emotional or informational help offered to a person with MS.
   ○ Yes
   ○ No

3. Does the person with MS for whom you provide support or assistance experience any limitation in his/her walking ability or daily activities due to MS? Limitation in walking ability or daily activities means that the person with MS may use a cane, crutch(es), scooter, wheelchair or some other form of support (e.g. touching a wall or leaning on someone's arm) sometimes or all of the time.
   ○ Yes
   ○ No

4. Are you able to complete the survey in English?
   ○ Yes
   ○ No
Thank you for your interest in participating in this survey. Unfortunately, you do not meet the eligibility criteria for the study. We are currently looking for individuals who:

- are 18 years or older,
- have a close friend or family member with moderate to severe MS,
- provide at least 45 minutes/day of support or assistance to the close friend or family member with MS and are able to complete the survey in English.

If you would like more information about the study, please email a.farotimi@queensu.ca or call 1-855-533-3407 toll-free.

You meet all of the criteria for participating in the study. If you are still willing and able to participate, please click the "Next" button (below) to begin your survey.

Thank you for agreeing to participate in this survey. We appreciate your time and cooperation. Please read and answer each question to the best of your ability. There are no right or wrong answers. All your answers are completely confidential.

**PART 1: PHYSICAL ACTIVITY PARTICIPATION**

Physical activity is any body movement that works your muscles and requires more energy than resting. Walking, gardening, dancing, swimming, and yoga are a few examples of physical activity. The first group of questions will ask you about the time you spent being physically active in the past 1-week. Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

1a. Think about all the vigorous activities that you did in the past 1-week. Vigorous activity includes any planned or incidental activity that causes you to sweat and be out of breath or during which you could not say more than a few words without pausing for a breath. Think only about those physical activities that you did for at least 10 minutes at a time.

<table>
<thead>
<tr>
<th>How many days during the past 1-week did you do vigorous physical activity?</th>
<th>How many minutes on each occasion?</th>
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<tbody>
<tr>
<td>○ 0</td>
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<td>○ 1</td>
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<td>○ 2</td>
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<td>○ 6</td>
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<td>○ 7</td>
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</table>
1b. Now, think about all the moderate intensity activities that you did in the past 1-week. Moderate intensity activity includes any planned or incidental activity that causes you to sweat a little and to breathe harder than normal or during which you could talk but not sing. Think only about those activities that you did for at least 10 minutes at a time.

How many days during the past 1-week did you do moderate intensity physical activity? How many minutes on each occasion?

- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7

1c. Now, think about the time you spent walking in the past 1-week. This includes at work and at home, walking to travel from place to place, and any other walking that you have done solely for recreation, sport, exercise, or leisure.

How many days during the past 1-week did you walk for at least 10 minutes at a time? How many minutes on each occasion?

- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7

1d. Think about the time you spent sitting on weekdays during the past 1-week. Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.

How many minutes did you spend sitting on each day?
2. Please list the **types of activities you participated in** during the past one week

<table>
<thead>
<tr>
<th>Type of activity</th>
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3. Would you say that you are physically more active, less active or about as active as other persons your age in the general population?

- More active
- Less active
- About as active
- Other, please specify... __________________________

**PART 2: COMMUNITY RESOURCES**

Community resources are the people, places, programs and services that members of a given community can turn to for tools or assistance to support participation in physical activity. The next group of questions asks about community resources you may have used in the past year to support your participation in physical activity.

1. Which of the following community resources have you used to support your participation in physical activity in the past year? (Check **ALL** that apply)

- Programs that are customized and flexible in presentation and delivery (e.g. face to face or over the internet, individual or group-based setting etc.)
- Programs that provide opportunities to learn about options for incorporating physical activity in daily life
- Programs that target the mind and body
- Programs that support joint participation of people with MS and their family caregivers in physical activity (i.e. both groups can benefit from and enjoy the program)
Programs that are held in accessible locations (e.g. accessible parking, equipment, bathrooms, lockers etc.)

Program that have facilitators who have adequate MS specific knowledge and training

Programs that have affordable total cost of participation (e.g. parking, membership fees etc.)

Programs that provide people with MS and their family caregivers with the necessary skills to deal with disease-related problems

Programs that increase confidence (self-efficacy) to deal with disease-related problems among people with MS and their family caregivers

Programs that include a wide variety of relevant options for physical activity participation in the same location

Information about available resources to support physical activity participation (e.g. publicity and advertisement of programs, information on fee assistance opportunities etc.)

Accessible, reliable and safe bus routes to important places such as community recreation centers, shopping areas etc.

Walking and biking trails that form a viable transportation option to and from activities

Communities differ in the kinds of resources that are available to support physical activity participation. The following group of questions asks about how important these resources are to you versus how satisfied you are personally about the availability of these resources in your community:

2. Please rate how important these resources are to you versus how satisfied you are personally about the availability of these resources in your community:

<table>
<thead>
<tr>
<th>Importance</th>
<th>Satisfaction</th>
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<tbody>
<tr>
<td>Very Important</td>
<td>Very Satisfied</td>
</tr>
<tr>
<td>Important</td>
<td>Satisfied</td>
</tr>
<tr>
<td>Neutral</td>
<td>Neutral</td>
</tr>
<tr>
<td>Somewhat Important</td>
<td>Dissatisfied</td>
</tr>
<tr>
<td>Important</td>
<td>Very</td>
</tr>
<tr>
<td>Unimportant</td>
<td>Dissatisfied</td>
</tr>
</tbody>
</table>

Programs that provide opportunities to learn about options for incorporating physical activity in daily life
| Programs that target the mind and body | Neutral | Somewhat Important | Unimportant | Very Important | Important | Neutral | Somewhat Important | Important | Neutral | Somewhat Important | Important | Neutral | Unimportant | Very Important | Important | Neutral | Somewhat Important | Important | Neutral | Unimportant | Very | Dissatisfied | Very | Dissatisfied | Very | Satisfied | Very | Satisfied | Very | Satisfied | Very | Satisfied |
| Programs that support joint participation of people with MS and their family caregivers in physical activity (i.e. both groups can benefit from and enjoy the program) | Neutral | Somewhat Important | Unimportant | Very Important | Important | Neutral | Somewhat Important | Important | Neutral | Somewhat Important | Important | Neutral | Unimportant | Very Important | Important | Neutral | Somewhat Important | Important | Neutral | Unimportant | Very | Dissatisfied | Very | Dissatisfied | Very | Satisfied | Very | Satisfied | Very | Satisfied |
| Programs that are held in accessible locations (e.g. accessible parking, equipment, bathrooms, lockers etc.) | Neutral | Somewhat Important | Unimportant | Very Important | Important | Neutral | Somewhat Important | Important | Neutral | Somewhat Important | Important | Neutral | Unimportant | Very Important | Important | Neutral | Somewhat Important | Important | Neutral | Unimportant | Very | Dissatisfied | Very | Dissatisfied | Very | Satisfied | Very | Satisfied | Very | Satisfied |
| Program that have facilitators who have adequate MS specific knowledge and training | Neutral | Somewhat Important | Unimportant | Very Important | Important | Neutral | Somewhat Important | Important | Neutral | Somewhat Important | Important | Neutral | Unimportant | Very Important | Important | Neutral | Somewhat Important | Important | Neutral | Unimportant | Very | Dissatisfied | Very | Dissatisfied | Very | Satisfied | Very | Satisfied | Very | Satisfied |
Programs that have affordable total cost of participation (e.g. parking, membership fees etc.)

Very Important
Important
Neutral
Somewhat Important
Unimportant

Very Satisfied
Satisfied
Neutral
Dissatisfied

Programs that provide people with MS and their family caregivers with the necessary skills to deal with disease-related problems

Very Important
Important
Neutral
Somewhat Important
Unimportant

Very Satisfied
Satisfied
Neutral
Dissatisfied

Programs that increase confidence (self-efficacy) to deal with disease-related problems among people with MS and their family caregivers

Very Important
Important
Neutral
Somewhat Important
Unimportant

Very Satisfied
Satisfied
Neutral
Dissatisfied

Availability of a wide variety of relevant options for physical activity participation in the same location

Very Important
Important
Neutral
Somewhat Important
Unimportant

Very Satisfied
Satisfied
Neutral
Dissatisfied

Information about available resources to support physical activity participation is easy to find (e.g. publicity and advertisement of programs, information on fee assistance opportunities etc.)

Very Important
Important
Neutral

Very Satisfied
Satisfied
Neutral
Dissatisfied
Accessible, reliable and safe bus routes are available to important places such as community recreation centers, shopping areas etc.

Walking and biking trails connect to form a viable transportation option to and from activities

3a. Are there any other resources that can support your participation in physical activity that you would like to have available in your community?

- Yes
- No

3b. Please list the resources

PART 3: BARRIERS TO PHYSICAL ACTIVITY PARTICIPATION

The next group of questions asks about barriers to your participation in physical activity.

1. Thinking about sole-participation (i.e. you alone) and co-participation (i.e. with the person with MS) in physical activity, please indicate how much of a barrier each of the following items is to you personally when you participate in physical activity alone versus with the person with MS

a. Lack of motivation to initiate and maintain participation in a physical activity program

- Very small barrier
- Small barrier
- Neutral
- Somewhat Important
- Important
- Very Important
- Very Important

Sole-participation (you alone)

Co-participation (with the person with MS)

- Very small barrier
- Small barrier
- Neutral
- Somewhat Important
- Important
- Very Important
- Very Important
<table>
<thead>
<tr>
<th>Category</th>
<th>Small barrier</th>
<th>Neutral</th>
<th>Big barrier</th>
<th>Very big barrier</th>
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<tbody>
<tr>
<td>b. Lack of confidence in ability to be physically active</td>
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<td>c. Lack of enjoyment of physical activity</td>
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<td>d. Lack of time to participate in physical activity</td>
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<td>e. Lack of child care/ elder care support</td>
<td>○</td>
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<td></td>
<td>f. Lack of choice and control over physical activity and level of participation</td>
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<td>○ Small barrier</td>
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<tr>
<th></th>
<th>g. Lack of accessible locations for physical activity (e.g. equipment, bathrooms, parking, elevators, ramps etc.)</th>
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<td>○ Very small barrier</td>
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<td>○ Small barrier</td>
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<td>○ Neutral</td>
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<th>h. Fitness level e.g. cardiovascular or strength</th>
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<td>○ Very small barrier</td>
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<tr>
<th></th>
<th>i. Embarrassment about personal appearance when participating in physical activity</th>
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<td></td>
<td>○ Very small barrier</td>
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<td>○ Small barrier</td>
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<table>
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<tr>
<th>j. Variability or unpredictability associated with MS</th>
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<tbody>
<tr>
<td>Small barrier</td>
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<td>Very small barrier</td>
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<td>k. Energy requirement for physical activity is too high</td>
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<td>Small barrier</td>
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<tr>
<td>Very small barrier</td>
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<tr>
<td>l. Total cost of participating in a physical activity program is high (e.g. parking, membership fees etc)</td>
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<td>Small barrier</td>
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<tr>
<td>Very small barrier</td>
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<td>m. Safety issues within the community (e.g. excessive crime or fear of crime in neighborhood, absence of street lighting at night, excessive car traffic etc.)</td>
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<td>-----------------------------------------------</td>
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<tr>
<td>Small barrier</td>
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<tr>
<td>Very small barrier</td>
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</table>
n. Bad weather (e.g. rain, snow, or excessive heat)

PART 4: DEMOGRAPHIC AND GENERAL HEALTH QUESTIONS

We would like to ask you some questions about your background:

1. Which of the following describes your gender? (Check one)
   - Male
   - Female
   - Transgender
   - Do not identify as male, female or transgender
   - I'd rather not say

2. What is your age?
   - 18-24
   - 25-34
   - 35-44
   - 45-54
   - 55-64
   - 65 or Above
   - I'd rather not say

3. What is your current marital status: (Check one)
   - Single, Never Married
   - Married
4. What is your relationship with the person who has MS?
You are his or her:
- Spouse
- Common-law partner
- Parent
- Child
- Uncle/Aunt
- Nephew/Niece
- Sibling/s
- Other, please specify... ______________________

5. Do you live with the person who has MS?
- Yes
- No

6. Including yourself, how many persons live in your household?
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10+

7. Who else lives with you? (Check all that apply)
- No one (I live alone)
- Spouse
- Common-law partner
☐ Parent/s
☐ Child/Children
☐ Sibling/s
☐ I’d rather not say
☐ Other, please specify... ______________________

8. Please check the box which best describes where you live
   ○ Rural area
   ○ Small population center, with a population of between 1,000 and 29,999
   ○ Medium population center, with a population of between 30,000 and 99,999
   ○ Large urban population center, consisting of a population of 100,000 and over
   ○ I'd rather not say

10. What is the highest level schooling that you completed?
   ○ No schooling
   ○ 8th grade or less
   ○ Some high school
   ○ High school graduation
   ○ Technical or trade school
   ○ Diploma
   ○ Bachelor’s degree
   ○ Master’s degree
   ○ Doctorate degree (PhD, JD, EdD, MD)
   ○ I’d rather not say

11. What is your current employment status? (Check one)
   ○ Full-Time (≥40 hours per week)
   ○ Part-Time (20–39 hours per week)
   ○ Part time (1–19 hours per week)
   ○ Self-employed
   ○ Not working (full time caregiver)
   ○ Unemployed (unable to find work)
   ○ Unemployed (unable to work disability)
   ○ Unemployed (choose not to work)
   ○ Homemaker (do not work outside the home)
   ○ Retired
12. What is your total personal gross income? (Check one)
   - Less than $5,000
   - $5,000 to less than $10,000
   - $10,000 to less than $15,000
   - $15,000 to less than $20,000
   - $20,000 to less than $25,000
   - $25,000 to less than $30,000
   - $30,000 to less than $40,000
   - $40,000 to less than $50,000
   - $50,000 to less than $60,000
   - $60,000 to less than $70,000
   - $70,000 to less than $80,000
   - $80,000 to less than $90,000
   - $90,000 to less than $100,000
   - $100,000 and over
   - I'd rather not say

13. In general, would you say your health is (check one):
   - Excellent
   - Very Good
   - Good
   - Fair
   - Poor
   - I'd rather not say

14. Has your doctor ever told you have...

<table>
<thead>
<tr>
<th>Condition</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension (i.e., high blood pressure)</td>
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<tr>
<td>Hyperlipidemia (i.e., high cholesterol)</td>
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<tr>
<td>Chronic Lung Disease (e.g., asthma, COPD)</td>
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<tr>
<td>Depression</td>
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<tr>
<td>Anxiety</td>
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</table>
Now, we would like to ask you some questions about your loved one with MS and his/her MS, as well as the type of assistance or support you provide: Assistance or support refers to any physical, emotional or informational help you provide the person with MS

15. How many years have you known the person who has MS?

16. Are you currently providing the person who has MS with assistance or support with daily activities?
   - ○ No
   - ○ Yes
   - ○ Don't Know

17. How many years have you been providing the person who has MS with assistance or support because of his or her MS symptoms?

18. The symptoms of MS can make it difficult for a person to do everyday activities. We are interested in which of these activities you typically provide the person who has MS assistance or support to do. Please select the best option (no, sometimes or regularly) for each activity:

<table>
<thead>
<tr>
<th>Activity</th>
<th>No</th>
<th>Sometimes</th>
<th>Regularly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Move around inside the house?</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Go up and down a flight of stairs?</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Get in and out of bed?</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Get in and out of the shower or tub?</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Get dressed?</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Manage his/her bladder?</td>
<td>○</td>
<td>○</td>
<td>○</td>
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<tr>
<td>Prepare a hot meal?</td>
<td>○</td>
<td>○</td>
<td>○</td>
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<tr>
<td>Provide transportation?</td>
<td>○</td>
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19. When we experience stress in our lives, we usually try to manage it by trying out different ways of "coping". Sometimes, our attempts are successful in helping us solve a problem or feel better, and other times they are not. Below is a list of things that people have reported they may do when confronted with problems related to caring for someone with MS. Please indicate how often you have tried each of the coping strategies in dealing with caregiving in general. There are no "right" or "wrong" answers. Please substitute [my family member with MS] for the name of the person who has MS whom you care for and/or support.
<table>
<thead>
<tr>
<th>Statement</th>
<th>Never/Does not Apply</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>I talk issues through with [my family member with MS] in an attempt to solve the problems</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>I offer [my family member with MS] physical assistance</td>
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<tr>
<td>I ignore the problem or pretend it doesn’t exist</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
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<tr>
<td>I look at the positives of the situation</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>I talk to others about the problem</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
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<tr>
<td>I turn to work or other substitute activities such as gardening, hobbies or sport, to take my mind off the problem</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
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<tr>
<td>I accept that this is how it is</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
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<tr>
<td>I blame myself</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
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<tr>
<td>I purchase assistive equipment such as wheelchair, incontinence aids or computer to assist [my family member with MS]</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
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<tr>
<td>I keep myself busy</td>
<td>o</td>
<td>o</td>
<td>o</td>
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<td>o</td>
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<tr>
<td>I try to point out the positives to [my family member with MS]</td>
<td>o</td>
<td>o</td>
<td>o</td>
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<tr>
<td>I yell or shout at [my family member with MS]</td>
<td>o</td>
<td>o</td>
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<tr>
<td>I keep out of [my family member with MS]’s way when he/she is in a bad mood</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>I seek assistance from others, for example, employ people to do the housework or ask friends to help out.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
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<tr>
<td>I tell [my family member with MS] that the problem is all their fault</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
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<tr>
<td>I arrange my schedule so I can be with [my family member with MS] when needed</td>
<td>o</td>
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<td>o</td>
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<tr>
<td>I wish the problem would go away</td>
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<tr>
<td>I seek information about the problem</td>
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</tbody>
</table>
I keep my problems to myself
I utilize respite services
I try to improve our financial situation, for example, work more hours, budget money
I try to snap [my family member with MS] out of it
I try to snap [my family member with MS] out of it
I take time for myself/spend time away from [my family member with MS]
I closely monitor [my family member with MS]
I tell [my family member with MS] what to do
I participate in activities we can do together in order to develop our relationship.
I criticize [my family member with MS]
I try to keep aware of [my family member with MS]’s needs and endeavor to meet these, for example, I know when to slow down or take a rest
I offer emotional support to [my family member with MS]
I nag [my family member with MS]
I laugh and try to find humor in the situation
I talk to health care professionals about the problem, for example, GP, specialist or psychologist
I drink or smoke more
I try to solve the problem on my own

This is the end of the survey. Thank you for your participation in this important research. All your answers will remain confidential and when survey results are reported, your answers will be combined with the answers of others so that you cannot be identified. The responses you provide would help the researchers understand the concerns and priorities of people with MS who have moderate to severe disability and their family caregivers about physical activity participation. Your participation will also provide information that may inform the development of programs to support regular participation of
people with MS and their caregivers in leisure-time physical activity. Please click the "Survey completed, I submit my responses" button (below) to complete your survey. If your loved one who has MS would like to participate in this study, please copy and paste the link below into another browser. They will be directed to the concerns report survey for people with MS:

http://queensu.fluidsurveys.com/s/peoplewithMS/