

Exploring the perceptions of participants of a novel telerehabilitation program designed to decrease sedentary behavior in adults with multiple sclerosis: a qualitative study.

by

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Abstract

Background: As a result of walking and balance impairments, deconditioning, fatigue, pain and depression, individuals with multiple sclerosis (MS) have an increased risk of accumulating long bouts of sedentary behaviour sitting compared to the general population. While sitting has been used as a strategy for fatigue management in the MS population, evidence suggests that excessive sitting increases comorbidity, such as cardiovascular disease, cancer, diabetes and obesity, in the general population. This highlights the need for an intervention to reduce sedentary behaviour in the MS population. The study of sedentary behaviour in the MS population is an emerging field of research. Only one study has investigated the potential of telerehabilitation to decrease sedentary behaviour in the MS population. No study has explored the experience of participants in a sedentary behaviour change programs delivered via a telerehabilitation medium in the MS population.

Purpose: To identify and describe the experience of sedentary adults with MS participating in a telerehabilitation sedentary behaviour change program.

Methods: This qualitative study took place within a 15-week feasibility study of the *Sit Less with MS* program, a telerehabilitation activity behaviour change program designed specifically for people with MS. The study design was interpretive description, a qualitative methodological framework. Ten individuals, nine females and one male, participated in semi-structured, one-on-one interviews. The participants varied in age, level of experience with technology, and mobility disability. All interviews were recorded and transcribed verbatim. Themes describing the participants' perceptions were identified using thematic analysis.

Results: Three primary themes described the participants' experience of the telerehabilitation program. Participants perceived that they can be active in everyday life, that the program provided key elements to experiencing success and they described the program as a wellness journey. Our study highlights that adults with MS had an overall positive experience in the telerehabilitation program as it was convenient and provided the opportunity for participants to foster relationships with the health professional delivering the program. Participants described key aspects of the

program, such as developing awareness and accountability of activity, and learning to set goals and self-monitor their activity, which promoted long term behaviour change. Participants also highlighted some aspects of the program that should be improved in future telerehabilitation programs.

Conclusions: This is the first qualitative study exploring the experience of adults with MS in a sedentary behaviour change program delivered over a telerehabilitation medium. This study provides new insights into the experience of adults with MS participating in a telerehabilitation sedentary behaviour change program, including that participants experienced success sitting less and moving more in their daily lives, and that participants were able to differentiate between the benefits and messaging of “sit less and move more” compared to increasing levels of physical activity and aerobic exercise. This study also highlights important implications for clinicians working with adults with MS and other neurological conditions in a rehabilitation setting, such as being open to using telerehabilitation as a tool to provide therapy services and discussing the benefits of decreasing sedentary behavior with clients.

Preface

This thesis is the original work by Jacqueline Rowley. The research project, of which this thesis is a part, received ethics approval from the University of Alberta Health Research Ethics Board.

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Table of Contents

ABSTRACT.....	II
PREFACE	IV
ACKNOWLEDGEMENTS	V
TABLE OF CONTENTS.....	VI
CHAPTER 1: INTRODUCTION AND STUDY OBJECTIVE.....	1
<i>INTRODUCTION</i>	1
<i>STUDY OBJECTIVE</i>	2
CHAPTER 2: LITERATURE REVIEW	3
TELEMEDICINE.....	3
TELEREHABILITATION.....	3
A CASE FOR SEDENTARY BEHAVIOUR CHANGE PROGRAMS DELIVERED VIA TELEREHABILITATION IN THE MULTIPLE SCLEROSIS POPULATION	4
PARTICIPANT PERSPECTIVES REGARDING TELEREHABILITATION	7
GAPS IN UNDERSTANDING THE PERCEPTIONS OF ADULTS WITH MULTIPLE SCLEROSIS PARTICIPATING IN TELEREHABILITATION PROGRAMS	8
A WAY TO FILL THE GAP: QUALITATIVE METHODOLOGY	9
RESEARCHER’S LENS	10
CHAPTER 3: JOURNAL ARTICLE.....	11
ABSTRACT	12
INTRODUCTION.....	13
METHODS.....	15
<i>Researcher’s Lens</i>	15
<i>Study Design</i>	15
<i>Setting</i>	16
<i>Participant Recruitment</i>	17
<i>Participants</i>	17
<i>Data Generation</i>	18
<i>Data Analysis</i>	19
<i>Rigour and Credibility</i>	21
<i>Ethical Considerations</i>	22
RESULTS.....	23
<i>Being Active in Normal, Everyday Life</i>	24
<i>Key Elements to Experiencing Success During the Program</i>	25
<i>Wellness Journey</i>	30
<i>Participant reflections on the results</i>	33
DISCUSSION.....	34
ACKNOWLEDGEMENTS	38
DECLARATION OF INTEREST STATEMENTS	38
CHAPTER 4: CONCLUSIONS AND CLINICAL APPLICATIONS	39
HOME-BASED SEDENTARY BEHAVIOUR CHANGE PROGRAMS.....	39
APPLICATION OF TELEREHABILITATION IN NEUROLOGICAL POPULATIONS	39
INCREASING SEDENTARY BEHAVIOUR EDUCATION IN NEUROLOGICAL POPULATIONS	40
INTERVENTIONIST PERSPECTIVES	41

REFERENCES	43
APPENDICES	53
<i>APPENDIX 1: INTERVIEW GUIDE</i>	53
<i>APPENDIX 2: MEMBER REFLECTIONS</i>	54
<i>APPENDIX 3: UNIVERSITY OF ALBERTA - ETHICS</i>	55
<i>APPENDIX 4: FILE MANAGEMENT</i>	59

Chapter 1: Introduction and Study Objective

Introduction

The purpose of this thesis was to learn about the experience of adults with multiple sclerosis (MS) participating a novel sedentary behaviour change program delivered via telerehabilitation. To date, there has only been one telerehabilitation program to decrease sedentary behaviour in the MS population.¹ Recently, Dr. Trish Manns and colleagues in the NeuroActive Lab in the Department of Physical Therapy at the University of Alberta have developed a novel telerehabilitation program to decrease sedentary behaviour in adults with MS: *Sit Less with MS*.² The *Sit Less with MS* program is a 15-week telerehabilitation activity behaviour change program designed specifically for people with MS. The aim of the program is to help individuals with MS to sit less and move more, by interrupting prolonged sedentary behaviour at frequent intervals and reducing overall sedentary time. This program is currently being tested in a feasibility study.²

Participants receive a weekly e-newsletter as well as an individual activity behaviour change coaching session delivered by an interventionist through a video-conferencing medium (Skype™ or FaceTime™) or by phone. The goal of the e-newsletters and coaching sessions is to facilitate the translation of knowledge and strategies for activity behaviour change based on the core determinants of the Social Cognitive Theory.³ During the weekly intervention sessions, the interventionists also reviewed and monitored the participants' activity through a commercial-grade activity monitor, the Fitbit™. The Fitbit™ recorded the participants' daily steps.⁴ Participants viewed the Fitbit™ data in real time via the Fitbit™ app or website. In addition, at three specific time points in the program, participants wore a research-grade activity monitor, called the ActivPAL™. The ActivPAL™ is a device which records changes in posture transitions (e.g., from sitting to standing), time spent in a posture (e.g., lying, standing or stepping), step counts and stepping speed.⁵ The ActivPAL™ data are shared with participants via email to increase awareness of their activity as well as changes over the course of the program.

There have been many physical activity behaviour change programs developed for adults with MS.^{6,7} The *Sit Less with MS* program is unique as it focuses on reducing sedentary behaviour and replacing it with light physical activity^{8,9} as it is likely more feasible and sustainable than programs focusing on structured exercise.² Clinicians who work with individuals with MS would

benefit from insight into the participants' experience with programs designed to decrease sedentary behaviour due to distinct differences between structured exercise and sedentary behaviour intervention programs.

At the end of the *Sit Less with MS* program, all participants completed a twenty-question feedback survey. Although the feedback was generally positive, a deeper understanding of participants' experience with a sedentary behaviour program delivered over a telerehabilitation medium would inform development of future programs.

Study Objective

The purpose of this study was to identify and describe the experiences of sedentary adults with MS participating with a telerehabilitation sedentary behaviour change program ("*Sit Less with MS*").

The corresponding research question was: What are the experiences of sedentary adults with MS participating with a telerehabilitation sedentary behaviour change program?

Chapter 2: Literature Review

Telemedicine

Substantial technological developments have allowed healthcare to be delivered over the Internet. This method of healthcare delivery, called telemedicine, is defined as the “use of information and communication technologies to improve patient outcomes by increasing access to care and medical information”.¹⁰ Telemedicine has the potential to dramatically improve access to healthcare information and services in rural communities and in less developed areas¹¹ at a low cost.¹² Over the past twenty-five years, telemedicine has been used in many clinical settings around the world.¹⁰ Clinical applications include mobile diabetic eye care in rural Indian communities¹³, mobile health system to reduce maternal and infant mortality in Guatemala¹⁴, dermatology consultations for general practitioners in Germany¹⁵, and parent training for children with autism spectrum disorder in the United States.¹⁶ In Canada, access to healthcare is limited in large part by an unequal geographical distribution of healthcare providers.¹⁷ Telemedicine has been used as a strategy to address this barrier. Over the past few years, the use of telemedicine in Canada has significantly increased from approximately 282,000 telehealth sessions in 2012 to 411,000 sessions in 2014.¹⁸ While there are many advantages to telemedicine, patients have voiced concerns regarding the use of telecommunication for healthcare delivery^{12,19–24}, including the breakdown in the relationship between patients and healthcare providers, the miscommunication between health professionals, the quality of health information and organizational difficulties.¹² Despite these concerns, telemedicine continues to be applied in many settings¹⁰, including teleradiology, telepsychiatry, telepathology¹⁰, and telerehabilitation.²⁵ Telemedicine allows for the delivery of health care to populations living in rural communities or less developed areas¹¹ and to those with mobility impairments⁶ at low cost.¹² Telerehabilitation is described in greater depth below.

Telerehabilitation

Rehabilitation is defined as any service provided to an individual with impairment in order to increase or maintain optimal function and quality of life in their own environment.^{26,27} Rehabilitation professionals, such as physical and occupational therapists, work with individuals to achieve their goals, and to increase and maintain independence and full participation in all

aspects of life.^{26,27} The demand for rehabilitation services is steadily increasing as evidence supports its effectiveness for decreasing morbidity and mortality, as well as increasing quality of life amongst individuals with disability.²⁸⁻³² Traditionally, individuals have received rehabilitation for short periods of time predominantly in a face-to-face format. Access and adherence to these services is often limited by distance to the service location, transportation, insurance coverage, level of disability and availability of clinicians.³³ To overcome these barriers, clinicians have explored the potential applications of telerehabilitation.

Telerehabilitation is defined as the remote delivery of rehabilitation services via information and communication technology⁶ (e.g., phone, Skype™, FaceTime™). Telerehabilitation has been used to provide timely, cost-effective, patient-centered services beyond the face-to-face service delivery^{6,34} to individuals who may otherwise not be able to access health services because of complex care needs²⁵, work or family commitments, rural location, or physical, psychological and cognitive impairments.^{6,17} Many telerehabilitation programs are currently being provided, including personalized exercise³⁵, chronic pain management²⁰ and diabetic foot ulcer programs.³⁶ A patient population with complex care needs who may significantly benefit from telerehabilitation are individuals with multiple sclerosis.

A Case for Sedentary Behaviour Change Programs Delivered via Telerehabilitation in the Multiple Sclerosis Population

Multiple sclerosis (MS) is a chronic inflammatory and degenerative disease of the central nervous system³⁷ affecting over 70,000 Canadians.³⁸ Although there is significant variation in the clinical presentation and disease progression of MS³⁹, some of the most common symptoms include mobility⁴⁰ and cognitive⁴¹ impairments, depression⁴² and fatigue.⁴³ As MS symptoms progress, individuals experience greater mobility disability and report having difficulty completing activities of daily living⁴⁴, such as cooking and cleaning, and participate in fewer social and community activities.⁴⁵ Lower levels of independence and participation have negative effect on the individual's sense of wellbeing and overall quality of life.⁴⁴

As a result of gait and balance impairments⁴⁶, deconditioning⁴⁷, fatigue, pain and depression⁴⁶, individuals with MS are less physical active and have an increased risk of accumulating long bouts of sedentary behaviour compared to the general population.^{46,47} The World Health Organization defines physical activity as “any bodily movement produced by

skeletal muscle that requires energy expenditure".⁴⁸ An individual is considered physically inactive if they perform an insufficient amount of moderate and vigorous intensity physical activity.⁴⁹ The current recommendations for physical activity state that adults aged 18–64 years should complete at least 150 minutes of moderate intensity aerobic physical activity, such as dancing or gardening, or complete at least 75 minutes of vigorous intensity aerobic physical activity, such as running, throughout the week.^{50,51} Physical activity has been associated with improvements in aerobic capacity, balance, muscular strength, walking mobility⁵², depression⁵³, fatigue⁵⁴ and quality of life⁵⁵ in the MS population. However, adults with MS are significantly less physically active than the general population.⁵⁶ Fewer than 20% of adults with MS are meeting the recommended levels of physical activity⁵⁷ and participation in physical activity decreases with age.⁵⁸ Individuals with MS may not be participating in physical activity as they experience disability progression, cardiopulmonary problems, have a lack of information regarding the benefits of physical activity⁵⁹ and encounter environmental barriers to traditional physical activity services, such as inaccessible equipment or facilities, lack of transportation or finances, and negative beliefs about physical activity.⁶⁰

Adults with MS are sitting more throughout the day than the general population.⁶¹ Sedentary behaviour is defined as “any waking behaviour categorized by energy expenditure ≤ 1.5 metabolic equivalents (METs) while in a sitting or reclining posture”.⁴⁹ Over the last fifteen years, a body of evidence has been developed and calls attention to the health risks of increased sedentary behaviour.^{49,62} Sitting has been used as a fatigue management strategy amongst individuals with MS.⁶³ Adults with increased sedentary behaviour have lower physical function⁶⁴ as well as higher risk of comorbidities, including cardio-metabolic markers^{65,66}, cancer⁶⁷, depression⁶⁸, type 2 diabetes^{69,70} and obesity⁷¹, compared to the general population. In addition, two meta-analyses found a higher rate of mortality⁷² and cardiovascular disease⁷³ in adults who sat for more than 10 hours per day.

The evidence of associations between sedentary behaviour and adverse health outcomes is alarming for the MS population as they have greater prevalence of comorbidities^{74,75}, including depression, anxiety, hypertension and hyperlipidemia³⁹, and are more sedentary compared to the general population.^{61,76} A growing body of evidence suggests that comorbidities negatively impacts the disease course of MS, including progression of symptoms, cognition, mortality and quality of life.³⁹ As MS related symptoms progress, individuals experience more mobility

disability^{40,46} which increases their risk of spending more time sitting during the day compared to the general population.^{46,47} A recent publication by Sasaki et al. (2018) reported that adults with MS sit for twice as long per day as the average population (480 mins/day compared to 240 mins/day).⁶¹ In addition, Ezeugwu et al. (2015) presented evidence that adults with MS with mobility disability accumulate on average more sedentary bouts per day compared to adults with MS without mobility disability.⁷⁶ This evidence highlights the need for an interventions to reduce sedentary behaviour in the MS population.^{1,46,76-78}

A proposed strategy to target health-related challenges in the MS population is to encourage individuals to adopt positive health behaviours, such as interrupting long sitting bouts and increasing light physical activity.^{39,76} Manns et al. (2012) proposed that a whole-day approach to physical activity promotion should be adopted in populations with mobility impairments.⁹ Programs should not focus exclusively on increasing moderate-intensity physical activity, but also on reducing sedentary behaviour and increasing light-intensity physical activity during the day.⁹ In addition, many national activity guidelines^{8,79-81} and an internationally accepted guideline published by the 2018 Physical Activity Guidelines Advisory Committee (PAG)⁸ highlight the benefits of not only increasing moderate to vigorous physical activity, but also of decreasing sedentary behaviour. The PAG guideline proposes that 1) limiting excessive time sitting would reduce the impact of premature mortality and several major comorbidities, including type 2 diabetes, cardiovascular disease and cancer, and that 2) replacing sedentary behaviour with light intensity physical activity would likely produce health benefits in the general population.⁸² The PAG guideline⁸ and Manns et al. (2012) call for a paradigm shift for managing activity behaviour: from program focusing on increasing aerobic physical activity to whole-day activity programs focusing on increasing light-intensity physical activity and decreasing sedentary behaviour.

Several behaviour change programs have been designed to increase physical activity in the MS population⁸³, some of which have been delivered through telerehabilitation.^{1,84-89} Although there is evidence that behaviour change programs increase levels of physical activity in the MS population in the short-term, there is limited evidence for the effectiveness of programs to promote long-term engagement in physical activity⁸³ as well as improving functional activities⁶, quality of life and fatigue.^{6,83} This evidence highlights the need to develop a new strategy to increase daily activity amongst individuals with MS. A proposed strategy is the development of sedentary behaviour change programs delivered via telerehabilitation.^{1,2}

Behaviour change programs have been delivered to adults with chronic diseases via telerehabilitation, including programs for diabetic management⁹⁰, cardiac rehabilitation⁹¹, lifestyle behaviour change for overweight and obese children⁹², and physical activity in cancer treatment.⁹³ Delivering a sedentary behaviour change program through a telerehabilitation medium is appropriate for the MS population as they have complex care needs³⁹ and often have transportation limitations.⁶ Some of these complex care needs include receiving long-term multidisciplinary management⁹⁴ for behaviours that could be changed through the web^{76,95-98}, including increased sedentary behaviour⁷⁶, unhealthy lifestyle behaviours⁹⁶ and decreased physical activity.⁹⁸ In addition, the MS population is young at age of diagnosis⁹⁹ and reports high Internet use¹⁰⁰ making telerehabilitation a feasible intervention mode.

To date, only one study has investigated the potential of telerehabilitation to decrease sedentary behaviour with individuals with MS.¹ Klaren et al. (2014) demonstrated the effectiveness of behavioural interventions in decreasing sedentary behaviour and suggested that future studies should investigate the impact of reducing sedentary behaviour on secondary outcomes, such as function, symptoms and quality of life.¹ In addition, Aminian et al. (2019) recently published the methodology of a feasibility study to decrease sedentary behaviour in the MS population via telerehabilitation.² The *Sit Less with MS* program is a sedentary behaviour change program delivered over a web-based medium and is designed specifically for people with MS. The aim of the program is to help individuals with MS to sit less and move more, by interrupting prolonged sedentary behaviour at frequent intervals and reducing the overall sedentary time.² This feasibility study² provided the backdrop for the proposed qualitative study that comprises this thesis. The experiences of participants in sedentary behaviour change programs have not been investigated. This thesis fills a gap in our understanding of patient perspectives regarding a behaviour change program focused on reducing sitting behaviour.

Participant Perspectives Regarding Telerehabilitation

The perspectives of individuals with chronic diseases engaging in telerehabilitation services provided by allied health professionals, such as nursing and physical therapy, has been investigated.^{20,101,102} A few examples include the use of telemedicine for diabetic foot ulcer care³⁶, smartphone-based health coaching for type 2 diabetes¹⁰² and Internet-based nursing intervention for women with chronic musculoskeletal pain.²⁰ In the MS population, studies have described the

perceptions of participants using home-based computer assisted cognitive training¹⁹, mobile app programs for disease²³ and energy management^{103,104}, and Internet-based programs to promote physical activity.^{21,22,24,103,105,106} Individuals with MS have also expressed what they want from an Internet-based resource to increase physical activity, such as reliable information and resources, good visuals and an interactive platform.^{24,106}

Advantages of participating in physical activity interventions reported by individuals with chronic disease and mobility impairments include convenience and increased accessibility to the program as transportation barriers were eliminated¹⁰⁵, establishing a structure and support system for change via a telerehabilitation medium^{21,24,103} and fostering a relationships with the professionals providing the programs (e.g., physical therapist)^{21,103}. Participants with mobility impairments in Internet-based physical activity programs described similar changes in physical function¹⁰⁵ and keys to success, such as learning to support themselves, adjusting their goals, and managing changes in physical function and emotions²¹, as those in face-to-face programs.¹⁰⁷ Conversely, reported challenges included difficulties organizing group sessions, poor time management and technological issues.¹⁰³ These challenges prompted participants to suggest ways to improvements to the Internet-based programs, such as the use of simple language in all Internet-based communications,²¹ and inclusion of activity monitoring devices with alarms to remind participants to move throughout the day.¹⁰⁵

Gaps in Understanding the Perceptions of Adults with Multiple Sclerosis Participating in Telerehabilitation Programs

To date, no study has investigated the experiences of individuals with MS participating in a telerehabilitation program to decrease sedentary behaviour. It is important to explore the perspectives of adults with MS participating in the *Sit Less with MS* program as the program has a different focus compared to previous physical activity behaviour change programs.^{6,84,89,108,109} The *Sit Less with MS* program focuses on increasing sitting interruptions and light physical activity throughout the day, as compared to the more typical focus which is increasing moderate to vigorous physical activity to a certain threshold.¹¹⁰ Although there have been qualitative studies exploring the perceptions of adults with MS in Internet-based physical activity programs^{21,103,106,111}, we do not have an understanding of the perspectives of adults with MS participating in a sedentary behaviour program delivered via telerehabilitation.

As part of the process to design the *Sit Less with MS* program, a small group of adults with MS were interviewed to understand their perceptions of sedentary behaviour. They described difficulty balancing the priorities of sitting and moving throughout the day, had varying knowledge, beliefs and perceptions of sitting and moving, and experienced barriers and facilitators to sitting and moving more.¹¹² Now, we have the opportunity to learn about perspectives of a different group of participants, after they have completed the program.

A Way to Fill the Gap: Qualitative Methodology

Qualitative methodology was used to explore the perceptions of individuals with MS participating in a sedentary behaviour telerehabilitation program. There are several choices for qualitative methodologies that could be applied to guide the development of the research methods and analysis.¹¹³ Given that the objectives of this study are framed in an applied health context, it is important to choose a methodological framework from which the study results could be applied to clinical practice. In addition, the methodology should allow the researcher's clinical experience to supplement the research findings. Sally Thorne's interpretive description¹¹⁴ has been used extensively in nursing research^{36,115-118} and allied health.¹¹⁹⁻¹²¹ It was chosen as the methodological framework for this study.

Interpretive description is an inductive, qualitative methodological framework designed for applied health research setting.¹²² This methodological framework reflects that each individual has a unique experience of a phenomenon as a result of characteristics that shape "who we are"¹²², as well as our beliefs that are shaped by past experiences, assumptions and perceptions of the "real world".¹¹³ Research questions are developed from problems encountered in clinical practice and their answers should be meaningful to both clinicians and the population being studied.¹¹⁴

Using the interpretive description approach, health care professionals gain new insights which can be applied to their clinical field.¹²² Interpretive description encourages the clinical researcher to consider insights from many data collection sources¹²², such as one-on-one interviews, focus groups, field notes, as well as clinical experience. The result is an in-depth conceptual description of a phenomenon. A conceptual description highlights new developments and insights that can be considered for developing our understanding of the phenomenon.¹¹⁴

Researcher's Lens

The lens that I bring to this thesis is one of a novice physical therapist and researcher. As a novice researcher, I would describe myself as a constructivist¹¹³ as I seek to understand individuals perceptions of a specific experience, recognize that each individual has a unique perspective of an experience and analyze data using an interpretive approach. As a novice clinician, I am influenced by the Health Belief Model¹²³ and the language of the International Classification of Functioning, Disability and Health.¹²⁴ When discussing behaviour change with clients, I seek to understand how my client perceives a health behaviour. If their perceptions of a health behaviour are negatively impacting their willingness to change a health behaviour, I provide education regarding the health behaviour, change their environment to set up “cues to action” and increase their level of self-efficacy.¹²³ My experiences as a physical therapist working with neurology patients in a rehabilitation hospital setting also shape my lens as I have a perspective on which insights could be beneficial for therapists working with adults with MS. Since working as a research assistant for the *Sit Less with MS* study, I have studied and applied the concepts of Bandura's Social Cognitive Theory.³

Chapter 3: Journal Article

Exploring the perceptions of participants of a novel telerehabilitation program designed to decrease sedentary behavior (“Sit Less with MS”) in adults with multiple sclerosis: a qualitative study.

By Jacqueline Rowley, Daniel Gillespie, Leslie Wiart and Patricia (Trish) Manns.

JR was the primary investigator, interviewer as well as lead the development of the themes and writing of the manuscript. TM supervised the project and provided guidance in the development of themes and writing of the manuscript. JR and TM co-lead the analysis. DG was an interviewer and provided feedback on the themes. LW provided feedback on the methodology, results and discussion. All authors read and approved the final manuscript.

This article will be submitted to Disability and Rehabilitation. Following their guidelines, the following section is the journal article submission.

Abstract

Purpose: To identify and describe the perceptions of sedentary adults with MS participating in a telerehabilitation sedentary behaviour change program.

Methods: This qualitative study took place within a larger study; a 15-week feasibility study of the *Sit Less with MS* program, a telerehabilitation activity behaviour change program designed specifically for people with MS. The study design was interpretive description, a qualitative methodological framework. Ten individuals, nine females and one male, participated in semi-structured, one-on-one interviews. The participants varied in age, level of experience with technology, and mobility disability. All interviews were recorded and transcribed verbatim. Themes describing the participants' perceptions were identified using thematic analysis.

Results: Three primary themes described the participants' perception of the telerehabilitation program: that they can be active in everyday life, that the program provided key elements to experiencing success and described the program as a wellness journey. Our study highlights that adults with MS had an overall positive experience in the telerehabilitation program as it was convenient and provided the opportunity for participants to foster a relationship with the professional delivering the program. Participants described key aspects of the program, such as developing awareness, accountability and self-monitoring skills, and learning to set goals, which in turn promoted long term behaviour change.

Conclusions: This is the first qualitative study exploring the perceptions of adults with MS in a sedentary behaviour change program delivered over a telerehabilitation medium. This study provides new insights into the experience of adults with MS participating in a telerehabilitation sedentary behaviour change program, including that participants experienced success sitting less and moving more in their daily lives, and that participants were able to differentiate between the benefits and messaging of "sit less and move more" compared to increasing levels of physical activity and aerobic exercise. This study also highlights important implications for clinicians working with adults with MS and other neurological conditions in a rehabilitation setting, such as being open to using telerehabilitation as a tool to provide therapy services and discussing the benefits of decreasing sedentary behavior with clients.

Keywords

Perspectives, interpretive description, multiple sclerosis, telerehabilitation, sedentary behaviour.

Introduction

“You have to stand, as much as anything because it gets uncomfortable to sit for too long... It’s just a constant battle really through the day to overcome that, and you get less and less proficient at winning that battle”.¹¹² This quote highlights a challenge encountered by many adults with multiple sclerosis (MS); the battle between sitting and standing.^{61,76,112} The potential of providing telerehabilitation programs targeted at decreasing sedentary behaviour is just beginning to be explored in the MS population.^{1,2}

MS is a chronic inflammatory and degenerative disease of the central nervous system³⁷ affecting over 70,000 Canadians.³⁸ As a result of walking and balance impairments⁴⁶, deconditioning⁴⁷, fatigue, pain and depression⁴⁶, individuals with MS engage in less physical activity compared to the general population and may have an increased risk of accumulating long bouts of sedentary behaviour.^{46,47} The World Health Organization defines physical activity as “any bodily movement produced by skeletal muscle that requires energy expenditure”.⁴⁸ An individual is considered physically inactive if they perform an insufficient amount of moderate and vigorous intensity physical activity.⁴⁹ Physical activity has been associated with improvements in aerobic capacity, balance, muscular strength, walking mobility⁵², depression⁵³, fatigue⁵⁴ and quality of life⁵⁵ in the MS population. However, adults with MS are significantly less physically active than the general population⁵⁶, with fewer than 20% of adults with MS are meeting the recommended levels of physical activity.⁵⁷ Individuals with MS may not be participating in physical activity as they experience disability progression, cardiopulmonary problems, have a lack of information about the benefits of physical activity⁵⁹ and encounter environmental barriers to traditional physical activity services, such as inaccessible equipment or facilities, lack of transportation or finances, and negative beliefs about physical activity.⁶⁰

Over the last fifteen years, a body of evidence has been developed and calls attention to the health risks of increased sedentary behaviour.^{49,62} Sedentary behaviour is defined as “any waking behaviour categorized by energy expenditure ≤ 1.5 metabolic equivalents (METs) while in a sitting or reclining posture”.⁴⁹ While sitting has been used as a strategy for fatigue management in the MS population⁶³, evidence suggests that excessive sitting decreases physical function⁶⁴ as well as increases the risk of mortality⁷² and comorbidity, such as cardiovascular disease^{65,66,73}, cancer⁶⁷, diabetes^{69,70}, depression⁶⁸ and obesity⁷¹, in the general population. This

evidence is alarming for the MS population as, in addition to the increased comorbidities discussed above^{74,75}, they also exhibit greater amounts sedentary behaviour^{61,76} compared to the general population. A recent publication by Sasaki et al. (2018) reported that adults with MS sit for twice as long per day compared to the average population (480 min/day compared to 240 min/day).⁶¹ In addition, a publication by Ezeugwu et al. (2015) presented evidence that adults with MS with mobility disability accumulate on average more sedentary bouts per day compared to adults with MS without mobility disability.⁷⁶ This highlights the need for an intervention to reduce sedentary behaviour in the MS population.^{1,46,76-78}

Based on strategies recommended by Manns et al. (2012)⁹ and the 2018 Physical Activity Guidelines Advisory Committee⁸, a new whole day activity program should be designed. A whole day approach to physical activity promotion, focusing on not only increasing moderate-intensity physical activity, but also reducing sedentary behaviour and increasing light-intensity physical activity during the day, may increase long-term adherence to physical activity behaviour change.⁹ The delivery of the program through a telerehabilitation medium may be appropriate for adults with MS since adults with MS are young at age of diagnosis⁹⁹ and report high Internet use.¹⁰⁰ In addition, telerehabilitation, the remote delivery of rehabilitation services via information and communication technology⁶ (e.g., phone, SkypeTM, FaceTimeTM), has the potential to provide rehabilitation services at any place or time^{6,34} to adults with MS while eliminate barriers to participating in face-to-face programs, such as financial⁶ and transportation limitations.¹⁰⁵

To date, only one study has investigated the potential of telerehabilitation to decrease sedentary behaviour in the MS population.¹ Klaren et al. (2014) demonstrated the effectiveness of a behavioural intervention in decreasing sedentary behaviour in the MS.¹ Recently, we (2019) published the methodology of a telerehabilitation feasibility study to decrease sedentary behaviour in the MS population.² The *Sit Less with MS* program is a sedentary behaviour change program delivered over a telerehabilitation medium and is designed specifically for people with MS. The aim of the program is to help individuals with MS to sit less and move more, by interrupting prolonged sedentary behaviour at frequent intervals with the overall goals of reducing sedentary time.²

The limited research testing a sedentary behaviour intervention¹ did not provide insights into the perspectives of adults participating in sedentary behaviour change programs delivered through a telerehabilitation medium. The perspectives of adults with MS participating in the *Sit*

Less with MS program should be described as the program has a different focus compared to previous physical activity behaviour change programs: increasing sitting interruptions and light physical activity throughout the day via a telerehabilitation medium. These perspectives will be described using qualitative methods.^{114,125} The aim of this study was to identify and describe the perceptions of sedentary adults with MS participating in a telerehabilitation activity behaviour change program.

Methods

Researcher's Lens

The lens that I bring to this thesis is one of a novice physical therapist and researcher. As a novice researcher, I would describe myself as a constructivist¹¹³ as I seek to understand individuals perceptions of a specific experience, recognize that each individual has a unique perspective of an experience and analyze data using an interpretive approach. As a novice clinician, I am influenced by the Health Belief Model¹²³ and the language of the International Classification of Functioning, Disability and Health.¹²⁴ My experiences as a physical therapist working with neurology patients in a rehabilitation hospital setting also shape my lens. Since working as a research assistant for the *Sit Less with MS* study, I have studied and applied the concepts of Bandura's Social Cognitive Theory.³

Study Design

Interpretive description¹¹⁴ was the qualitative research approach used in this study. This method is described as an inductive, qualitative methodological framework designed for an applied health research settings.¹²² Research questions are developed by encountering problems in clinical practice and their answers provide new insights into the clinical field.^{114,122} Interpretive description encourages the clinical researcher to consider insights from many data collection sources,¹²² such as one-on-one interviews, focus groups, field notes, as well as clinical expertise and experience. The result of this approach is an in-depth conceptual description of a phenomenon. A conceptual description highlights new developments and insights that can be considered for developing our understanding of the phenomenon.¹¹⁴

Setting

This qualitative study took place within a 15-week feasibility study of the *Sit Less with MS* program (see Figure 1). The *Sit Less with MS* program is a telerehabilitation activity behaviour change program designed specifically for people with MS. The aim of the program is to help individuals with MS to sit less and move more, by interrupting prolonged sedentary behaviour at frequent intervals and reducing overall sedentary time.²

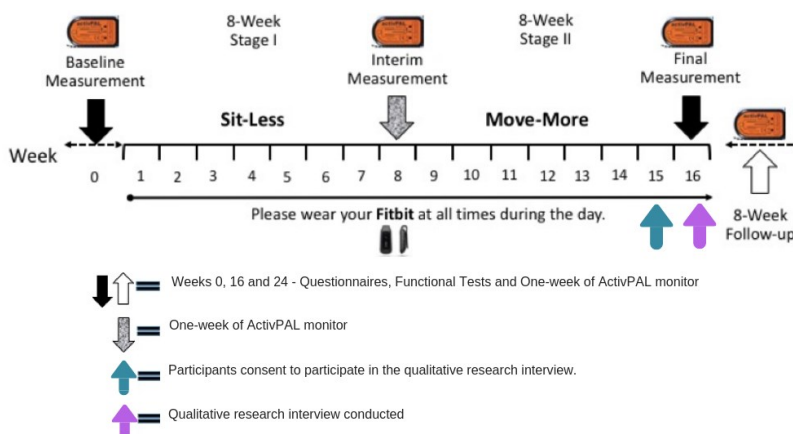


Figure 1. Time Line of The *Sit Less with MS* Program and Qualitative Study.

During every week of the feasibility study, participants received an e-newsletter as well as an individual activity behaviour change coaching session delivered by an interventionist through a video-conferencing medium (Skype™ or FaceTime™) or by phone. The goal of the e-newsletters and coaching sessions was to facilitate the translation of knowledge and strategies for activity behaviour change based on the core determinants of the Social Cognitive Theory.³ During the weekly coaching sessions, the interventionists also reviewed and monitored participants' activity through a Fitbit™. The Fitbit™ is a commercial-grade device activity monitor. Individuals can view their activity on the Fitbit™ device screen or on the web.⁴ In addition, the participants wore a research grade activity monitor called an ActivPAL™ during week 1, 8 and 16 of the program (see Figure 1). The ActivPAL™ is a research-grade device that records changes in posture transitions (e.g., from sitting to standing), period of time spent in a posture (e.g., lying, standing or stepping), step counts and stepping speed.⁵ The ActivPAL™ data are shared with participants to increase awareness of their activity as well as changes over the course of the program.

Participant Recruitment

Participants were eligible to participate in the qualitative study if they met the inclusion criteria for the *Sit Less with MS* feasibility study. The inclusion criteria for the feasibility study were: (1) confirmed diagnosis of MS for at least one-year, (2) Expanded Disability Status Scale¹²⁶ score between 1 and 6.5, (3) stable in terms of disease modifying drugs and rehabilitation over the previous 6 months, (4) relapse free within the previous 3 months, (5) physically inactive (defined as insufficiently active by the Godin-Shepard Leisure-Time Physical Activity Questionnaire¹²⁷) and (6) able to walk with or without a walking aid for 10 meters. Participants also had to have completed the 15-week *Sit Less with MS* program.

Participants for the qualitative portion of the study were purposively recruited during the final intervention session of the *Sit Less with MS* program. Purposive sampling was used to ensure variation within the sample. Participants were sampled based on three primary criteria: 1) having the characteristics of a good informant (e.g., experienced, articulate, focused, available)¹²⁸, 2) range of level of mobility impairment (based on the Expanded Disability Status Scale¹²⁶) and 3) range of familiarity and confidence using technology. These characteristics were necessary to generate rich and meaningful descriptions of the participants' perceptions of taking part in an Internet-based activity behaviour change program.¹¹⁴

Participants

Ten individuals, nine females and one male, participated. Seven participants had relapsing remitting MS, one participant had primary progressive MS and two participants had secondary progressive MS. The participants varied in age, level of experience with technology (independent technology troubleshooting to requiring step by step explanation of technology during every session), and mobility disability which is reflected in the range of baseline Expanded Disability Status Scale¹²⁶ scores from 2.5 to 6.5. Intervention coach 1 (D. G.) interviewed four participants and intervention coach 2 (J. R.) interviewed six participants. Intervention coaches did not interview participants they coached during the *Sit Less with MS* program. This strategy was applied to decrease the influence of the coaching style on the participants' perceptions of the program and to decrease the risk of bias. Participant characteristics are provided in Table 1.

Table 1. Participant Demographics.

Pseudonym	Gender	Age range	Type of MS	EDSS
1	F	30-34	RRMS	6.0
2	F	30-34	RRMS	6.0
3	F	70-74	SPMS	6.5
4	M	65-70	PPMS	6.5
5	F	50-54	RRMS	3.5
6	F	50-54	SPMS	6.5
7	F	40-44	RRMS	3.5
8	F	50-54	RRMS	5.5
9	F	55-59	RRMS	6.0
10	F	55-59	RRMS	2.5

MS – multiple sclerosis

EDSS – Expanded Disability Status Scale¹²⁶

RRMS – relapsing remitting multiple sclerosis

PPMS – primary progressive multiple sclerosis

SPMS – secondary progressive multiple sclerosis

Data Generation

Semi-structured Interviews

Semi-structured, one-on-one interviews were used to explore the participants' experience of the *Sit Less with MS* program. Interviews lasted 45 to 60 minutes and were completed using a video-conferencing medium (i.e., FaceTime™ or Skype™) or by phone. The interview guide comprised of open-ended questions (Appendix 1) was piloted by two interviewers (D.G and J.R.). The authors met to review the transcripts from the pilot interviews. The interview guide was modified to increase the richness and depth of the participant's answers, refine the focus of the questions in keeping with the research question, and to ensure coherence with the research question and methodology.¹¹⁴ During the interview, the interviewers added probing questions to enhance the depth, richness of data gathered and to explore unanticipated topics which arose during the interview.¹²⁹ All interviews were recorded and transcribed verbatim by the primary investigator.

Other Data

Data were also generated from field notes (e.g., interviewer impressions) and interventionists' notes. The interviewers reviewed the interventionists' notes prior to the interview to become familiarized with the participant's goals, level of familiarity with technology and any unique characteristics that may increase the depth of the interview, such as specific barriers or

facilitators encountered throughout the program. Since both interviewers were also interventionists in the *Sit Less with MS* program, their perceptions were included in the discussion.

Data Analysis

Since interpretive description is not a method, it does not have a rigid theoretical structure and analytic strategy.¹¹⁴ Thematic analysis is often applied as the analytic strategy in studies that use interviews as a primary data source.³⁶ The phases of analysis adopted in Miciak's (2015) doctoral dissertation guided the development of the data analysis process¹³⁰. These phases of analysis were chosen as they focused on identifying themes rather than specific words or phrases in the transcripts, and highlight that the researcher should be very familiar with the transcript before coding to prevent the over-emphasis on early interpretations.¹¹⁴ The two phases include: 1) becoming familiar with the data and 2) the formal analytic strategy.¹³⁰

Familiarization of the Data

Familiarization occurred in a step-wise fashion as outlined in Table 2, and began during the transcription of the audio recordings (see Table 2: Step 1). As described by Thorne (2008), transcription of the interviews provided the opportunity for the primary researcher (J. R.) to deeply engage with the data by paying "attention to nuances, words, phrases, and pauses, to hear more deeply what the language contains".¹¹⁴ During the transcription process, the primary researcher took notes in a memoing journal about the overall impressions of the interview (i.e., tone, rapport with the participant), interview style (i.e., did the interviewer follow the interview guide?), as well as if the probing questions were appropriate (Table 2: Step 2). Next, the primary and secondary researchers (J. R. and T. M.) independently completed a first full read through the transcripts (Table 2: Step 3) identifying units of information relevant to the research question and content which could develop knowledge in the clinical field. Finally, the researchers noted their impressions and interpretations of the transcripts (Table 2: Step 4). While becoming familiar with the data, the investigators were conscious not to attach specific words and/or descriptions to the memos to not influence the development of codes.¹¹⁴

Table 2. Description of the Familiarization of the Data Process.

	Description of Process
Step 1	Transcribe audio-recordings 1-3 days after the interview was conducted.
Step 2	Include thoughts about the interview and transcript in a reflexive journal.
Step 3	After the transcription is complete, complete the first full read through.
Step 4	Begin reflexive journaling and memoing.

Formal Analytic Strategy

Thematic analysis, “a method for identifying, analyzing and reporting patterns within data”¹²⁵, was adopted as the analytic strategy as it provides the investigator the freedom and flexibility to interpret the data. The researcher actively identifies themes, selects and reports which themes are meaningful to the development of knowledge in the clinical field.¹²⁵

Analysis began by grouping similar units of information to create themes.¹¹⁴ Themes were first independently identified by the two primary investigators (J. R. and T. M.). They then met to discuss preliminary themes. Four of the ten transcripts were identified as interviews that included rich information that guided the development of themes. These transcripts were sent to the third investigator (D. G.) to read and highlight themes. Subsequently, all authors met to discuss the themes that they identified in the data, explore similarities and differences between participants, as well as new concepts seen in the data. An iterative process was used to develop and understand relationships between themes. The authors were aware of not becoming over-invested in a theme or overlooking an opportunity to identify a meaningful relationship in the data. Throughout the analysis, the authors kept a memoing journal to encourage an open mind to observe and identify which ideas were and were not identified, compared, contrasted and reflected upon.¹¹⁴

The authors were also reflexive throughout the analysis process, considering how their own beliefs, past clinical and research experiences as well as motivations shaped their lens.¹³¹ As a clinician, I believe that all patients have the capacity to be “good rehabilitation candidates”. The phrase “good rehabilitation candidate” highlights a dichotomy that categorizes patients’ rehabilitation prognosis as “good” or “bad”. To break this dichotomy in my own practice, I apply my clinical experience and skills to adapt my treatment goals to ensure that I am providing patient and family centered care. The experiences that shaped my lens throughout this study include my work as a research assistant and interventionist for the *Sit Less with MS* program as well as my

clinical work as a physical therapist in neurological rehabilitation. My motivations for completing this study included learning how to design a qualitative study, enriching my understanding of the applications of telerehabilitation in the MS population and presenting a high-quality study as part of my master thesis. The secondary authors who contributed to the analysis (T. M. and D. G.) are also physical therapists with different beliefs, clinical and research experiences, and motivations. This increased the depth and breadth of reflexivity and discussion during the phase of analysis.

Latent themes were identified by “examin[ing] the underlying ideas, assumptions and conceptualizations” that shape the participants’ perceptions of the phenomenon.¹²⁵ NVivo (NVivo qualitative data analysis Software; QSR International Pty Ltd. Version 12, 2018) was used to organize the data.

Rigour and Credibility

This study’s rigour was evaluated through four principles applied to the products of interpretive description: epistemological integrity, representative credibility, analytic logic and interpretive authority.¹¹⁴

The epistemology of this study was subjectivist.¹³² A subjectivist voice was demonstrated throughout the study by having a “defensible line of reasoning from the assumptions made about the nature of knowledge through to the methodological rules decisions about the recent process explained”.¹¹⁴

Since this is the first study aimed to understand the perceptions of individuals with MS receiving sedentary behaviour change coaching through a telerehabilitation medium, the findings of this study must be consistent with the sampling method used to explore this phenomenon. The researcher recognizes that since this is the first study investigating their phenomenon and purposive sampling was used to recruit participants, it may be too soon to apply the findings outside of the study group. Long term engagement with the *Sit Less with MS* program as an interventionist and triangulation of the findings will be strategies used to increase the credibility and applicability of the findings.¹¹⁴

An audit trail through reflexive journaling and timeline documentation demonstrated analytic logic, and provided evidence of inductive reasoning throughout the study.¹¹⁴ The trustworthiness of the researcher’s interpretations¹¹⁴ were verified using member reflection¹³³ (Appendix 2). The study results, Table 3, were shared with the participants via email and they

were encouraged to comment and reflect on the findings, generating additional insights and dialogue.¹³³

Ethical Considerations

This study was approved by the University of Alberta Research Ethics Board (Appendix 3). The investigators informed the participants that their participation was voluntary and that they could withdraw from the study at any time without consequences. Participants were made aware of the risk of being identified by members of the community in the dissemination of the findings and of emotional harm (i.e., feeling unsettling emotions (discouragement, sadness or anxiety) when reflecting back on their experience.¹³⁴ The investigators ensured participant anonymity by removing names and identifying features from the transcripts.

All audio-recordings, transcripts and analysis documents were saved on password protected research hard drive at Corbett Hall, University of Alberta. Participant numbers were used to identify the files (Appendix 4).

Results

Three primary themes described the participants' perception of the telerehabilitation program. The participants perceived that they could be active in everyday life, that the program provided key elements to experiencing success and that the program was a wellness journey. Each theme will be defined and explained below. Table 3 provides a summary of themes and definitions.

Table 3. Themes and Definitions.

		Definition
Theme 1	Being active in normal, everyday life	Descriptions of how participants perceived they could be active in normal, everyday life.
Theme 2	Key elements to experiencing success	Descriptions of what participants thought were key elements to experiencing success during the program.
	<ul style="list-style-type: none"> • Awareness of activity 	Descriptions of how participants perceived their awareness of activity changed during the program.
	<ul style="list-style-type: none"> • Accountability 	Descriptions of program elements that participants perceived increased their accountability to their activity goals.
	<ul style="list-style-type: none"> • Internet-based medium 	Descriptions of how participants perceived that the Internet-based medium increased the accessibility of the program and allowed them to participate.
	<ul style="list-style-type: none"> • Small, meaningful steps towards goal 	Descriptions of how participants experienced success through small, meaningful steps towards their goal.
Theme 3	Wellness journey	Descriptions of how the participants perceived that their perspectives towards themselves, activity and wellness changed, that they experienced challenges and triumphs over the course of the program and that the program was the beginning of their wellness journey.
	<ul style="list-style-type: none"> • Change in perspective 	Descriptions of how the participants perceived that their perspectives towards themselves, activity and wellness changed.
	<ul style="list-style-type: none"> • Challenges and triumphs 	Descriptions of the ups and downs participants encountered over the course of the program.
	<ul style="list-style-type: none"> • Beginning of a wellness journey and intentions to be active 	Descriptions of the participants' evolution of mind-set, goals and daily activity as a journey and intentions to be active in the future.

Being Active in Normal, Everyday Life

This theme includes descriptions of how participants perceived that they could be active in normal, everyday life. At the beginning of the program, several participants believed that exercise required a structured time in a gym. By the end of the program, many perceived that being active meant integrating enjoyable activities into everyday life. A participant shared her experience:

"I think it goes back to what I said earlier about thinking that exercise had to be a formal, like set aside time to count... I would just beat myself up before because I hadn't gone to the gym or done a formal exercise program of some kind so this really helped me change my perspective that I was doing more than I thought I was... I can see that I can be active in my normal everyday life" (P02).

Being active in everyday life embodied itself differently for each participant. Many participants described strategies to be active in and around their home. A participant shared her experience of being active in her home saying "walking around the house it's really easy to use because it's here. You know I'm waiting for the dryer to finish drying, oh I'll walk a little bit. You know it's amazing how you can make it fit in" (P09). Another participant said:

"I look for ways to walk. Like I look for ways to be more active that I can fit to my day. Such as, if someone wants to drive me home, I ask them to drop me off a few blocks from my house. Or I don't get a drive home and I take then bus and then I have to walk the rest of the way. Umm like things like that. Like I walk to lunch, I make things so that I am forced to do activity or else, no I find that works better for me, I know how work. And activity always works better when there is a goal morphed into my day, not something I have to go out of my way to do" (P05).

Some participants described adaptations they made to promote independence and safety during activity around their home. A participant with greater mobility impairment said "[my garden] is a cement raised garden. I have something solid to hold onto, so I can keep my balance without having to worry about it tipping and that. I can do that on my own" (P06). Another participant with moderate mobility impairment described:

"I discovered something called activator poles. Which are the most amazing thing because they are not just hiking poles, they are really good for balance and that's walking to my mailbox or walking around the neighbourhood is with those activator poles. It's very very safe, it's good exercise" (P08).

For many, being active in everyday life included social activities. A young participant described:

“I went dancing a few weeks ago and it was amazing. And it was so fun, and I think that’s sort of the key for me. Because I don’t really enjoy formal exercise, is to do something I do enjoy and then sort of the active part is a side bonus. And even having to go somewhere and meet someone, having to get there well that alone will keep me active to a certain extent” (P02).

A participant described her strategy to include activity while socializing:

“I play bridge and when you play competitive bridge north and south usually doesn’t move and east and west move. And I usually played north south which meant that I didn’t move so I switched. It’s a small thing, but compared to sitting for three hours, because that’s how long a bridge game takes and actually getting up and moving even a little bit makes a big difference and little things like that” (P05).

Key Elements to Experiencing Success During the Program

This theme includes descriptions of elements which were key to participants experiencing success during the program. The key elements described included: increasing awareness of activity, being accountable for self-monitoring and goal setting, using an Internet-based medium and taking small, meaningful steps towards goals.

Awareness of Activity

This subtheme describes how participants’ awareness of activity changed during the program. At the beginning of the program, several participants were quite surprised to learn how much they were sitting throughout the day. A participant expressed that it was “a reality check for sure. That you can get twelve thousand steps in a day, but if you are completely still the rest of the day, that’s not good either” (P07). The awareness of their current level of activity provided a foundation from which participants could build their understanding of the risks of sitting too much, as well as how to decrease long bouts of sitting and increase daily activity. A participant described how “throughout the program, I did learn that it’s harmful to sit all the time and [it made] me aware that I am sitting all the time... It made me aware that I was able to be more active and I didn’t know that until I tried it” (P03). Many participants described the Fitbit™ as a tool to increase awareness, monitor interruptions and count steps throughout the day. A participant shared her experience saying:

“[the Fitbit™] just makes me really aware of how much activity I actually did. Because if I actually did it, I have no way of tracking it, no way to record it. You have no idea of how many steps you did take. Umm if I did do any stairs or things. If you are walking around in your day to

day activities, you really have no idea of how many steps you take. So, the Fitbit™ tells you how many steps you actually take and how much activity you have actually completed” (P08).

A participant described that while a clinician had recommended that she move more throughout the day to relieve symptoms, she perceived that she did not have the knowledge to apply this recommendation into her daily life. Over the course of the program, she increased her awareness and skills to be active throughout the day:

“my neurologist always said that, “I know it sounds counterintuitive, but you have to go out and exercise, you will feel better, trust me”. And it’s really hard for somebody who is not feeling very well to think that exercising will make you feel better. And this actually made me go out and prove her theory, well it’s not a theory but just to see that what she was saying was true, whereas before I was like I am achy all the time and I can barely get out of bed, you want me to do exercise? So that, that helped me a lot. It actually got me out and about and more conscientious about the fact that how many steps I was taking and what I was doing in a day” (P05).

Accountability

This subtheme describes program elements which, as perceived by participants, increased their accountability to their activity goals. Participants described two key elements to being accountable for their activity: the weekly coaching sessions and use of an activity monitoring device. All participants discussed the benefit of weekly coaching sessions. One participant described her experience:

“I work very well with structure and accountability so umm that part was really good. Like being about to schedule, like oh no I have to talk to a coach, you know every week and like being able to put everything into my calendar. And umm being able to set goals as well but also having the accountability sort of outside of just me and setting goals for myself that I can just write off when I lose interest... I think most people hit that point where they lose interest or get discouraged umm. And at the time that I would normally quit, (the interventionist) sort of kept me going. So that was really helpful” (P02).

Another participant described how she used the Fitbit™ as a tool to keep her accountable to her activity goals. She shared that “the Fitbit™... keep[s] you walking, keep[s] you accountable to yourself, and before I was accountable to all you guys because you had full reign on the Fitbit™. But being accountable to yourself and moving, and setting a goal for yourself to move or a certain amount of steps a day” (P09).

Internet-based Medium

This subtheme includes descriptions of how participants perceived that the Internet-based medium increased their ability to participate in the program. Participants described how completing the coaching sessions over the phone or video-conferencing medium (e.g. Skype™ or FaceTime™) was convenient and eliminated transportation barriers. A young participant described that:

“it was great because I didn’t have to leave the house. So, if I had to leave the house every week, that would have been added extra energy that I needed to commit to. Umm, so basically because I could just Skype™ from home at a time that was convenient for me, it was perfect” (P01).

Another participant stated “well first of all, I don’t drive anymore because I lost my eyesight 17 years ago due to MS. So that wasn’t always convenient, I had to take a bus or walk. So, this was less stressful for me because I don’t have to worry about being some place. It’s very convenient” (P05).

Participants also perceived that talking over a video-conferencing medium was equivalent to being face-to-face. A participant stated:

“I really liked it because it’s nice to know who you're talking to and it’s nice to see (the interventionist). And it makes it worth the encouragement over the phone but it's really nice to have the facial expression and the contact with the person that you're talking to like that when you're getting coaching, I think that's a really important thing to have that. And especially when something like this, it’s an emotional thing having MS, and it's just really nice to know that the person on the other end is on your side. And like I said you can see the facial expressions, and you know we could laugh together and see each laugh and that kind of thing, so I thought it was great. Really really worth it to do it that way” (P09).

Despite some challenges with technology, a participant shared that talking over a video-conferencing medium was meaningful to her. She described that:

“it was good, very effective umm once I figured out how to use it, I’m a techy but not a techy... So ya, there were technological glitches of course, sometimes in and out. But umm it was very good, and very good to see (the interventionist’s) face every week and hear (the interventionist’s) voice, and for (the interventionist) to see me and hear my voice. Much more meaningful I think than just a phone call or if a person was just emailing back and forth you know because it made it more real” (P08).

Although most participants described that they preferred the Internet-based medium, some suggested aspects of the coaching sessions, activity monitoring devices and weekly newsletters which could be improved. An older participant stated that the program’s duration could have been

shorter. She described that “the chats were good. They helped me focus on goals, they helped me set goals that were reasonable and specific and all that good stuff... I think [we could have] end[ed] them in the middle, I think we gained everything that we were going to gain” (P03).

Participants had mixed views on the benefit of the activity monitoring devices. The ActivPAL™, a research-grade activity monitoring device⁵, was worn at three different time points during the program. Participants were encouraged to wear the Fitbit™, a commercial-grade activity monitoring device⁴, every day of the program. While some participants perceived that they “didn’t get much out of [the ActivPAL™]” (P09) and “didn’t pay enough attention to [the ActivPAL™] to compare it to the Fitbit™” (P04), others described that the activity monitoring devices increased activity awareness and were a source of motivation. A young participant said “at the very beginning, I saw my very first ActivPAL™ report it was like, wow, I have so much that I could be doing” (P01). Another participant described how the ActivPAL™ was a much more meaningful representation of her daily activity:

“the ActivPAL™ is a more valuable resource, if you don’t mind having it taped to you, than the Fitbit™... It knows which way is up. So, it shows not only your sitting versus walking, the Fitbit™ doesn’t even do that, it really doesn’t record when I stand up. I have to take several steps at a significant speed for me, in order for it to record any steps... The ActivPAL™ shows when I stand up, or when I lie down, or when I am sitting. It’s much, much clearer” (P03).

Another participant described that she liked the accessibility of the Fitbit™, but would have benefited from a device that monitored her sitting time and prompted her to stand. She described:

“the only thing I’d say the Fitbit™ is missing is that it doesn’t track your sitting time really well, like it takes extra effort to look at your data and try to figure out ok how long was I sitting so umm. So yes, the Fitbit™ was more accessible, I just wish it had that feature. Or even if it, like the best thing would be if it would, if you could program it to alert you... That it would know and it would alert me if I was sitting for more than 20 minutes. So that was something that was just a bit of extra work was trying to figure out the sitting times” (P02).

Participants also had mixed reviews of the newsletters. Some participants found the newsletters were a good source of information and motivation. One participant shared her experience saying “the information sheets that I got, I’ve printed every one of them off and I have gone back and looked them over... And I will keep those because I think that they are a real source of inspiration too, and just having suggestions for how you can deal with situations” (P08). Others

perceived that the topics of the newsletters' topic were repetitive, with significant overlap between the Sit Less and Move More stage newsletters.

Another participant stated that “with the newsletters, its more about having more of a variety of topics or getting at different things other than the ones that were in the newsletters” (P04). Participants suggested various topics which could increase the diversity and relevance of the newsletters. Several participants indicated that they would have liked to receive more information and resources, while another suggested that the newsletters include practical information:

“maybe some coping things. That’s a good one. One of the things I have issues with is heat. If there are some little notes about how you could cope, like you could get a heat vest or umm something like that, like little notes on how to cope or how to get like a cane or something like little tidbits and information like that” (P05).

Another participant noted that the tone of the newsletters was always positive. He described that the newsletters should better represent the variations in emotional and physical symptoms that one experiences with MS. He stated that “the newsletters were always positive ones. From how a person feels better, but none of them said I feel worse. That happens with this disease” (P04).

Small, meaningful steps towards goals

This subtheme includes descriptions of how participants experienced success through small, meaningful steps towards their goal. A participant shared her experience:

“Because the program introduced things in such a small way, umm, and once you can accomplish those smaller goals, you ok, now we are going to look at walking to the mailbox, and I did it and I kept doing it and, ok, and now I am going to walk to the mailbox and walk past four houses. And I did it. I just, I think the program really helped me to, umm, set small achievable goals, and concur them, and then once I had met that goal, it built my confidence to try the next thing” (P01).

Another young participant described how consistently making incremental changes towards her goal helped her experience success:

“what was new for me was setting realistic goals. Like those little baby steps and that that is actually enough and that that makes a big difference. Umm I always use to set very ambitious goals umm which weren’t necessarily realistic and then it was really discouraging when I couldn’t meet them... I didn’t really know that like just making the incremental changes over time and being consistent is actually more conducive to change then the big fake goals” (P02).

Wellness Journey

There were three subthemes that described the perceptions of the participants' wellness journey. The key elements described included: participants perceived that their perspectives towards themselves, activity and wellness changed, that they experienced challenges and triumphs over the course of the program, and that the program was the beginning of their wellness journey.

Change in Perspective

This subtheme includes descriptions of change in participants' perspectives towards themselves, activity and wellness. A young participant shared how learning to be more self-compassionate was a big step towards learning to be flexible with her activity and goals:

"Start where you are. I think that that's a big, big concept that has changed my thinking... I am not comparing myself to what everyone else can do. I, it's just me comparing myself to myself. And realizing that I am doing great under the circumstances and that I do need, instead of feeling so discouraged because I don't reach that image that isn't even, that has nothing to do with me umm I can think about where I am and be ok with those baby steps and ya celebrate those small accomplishments. Ya so. I'd say I am learning to feel less discouraged about, by, what's out there in the world" (P02).

Participants described how they perceive that their confidence and problem-solving skills will continue to improve. One participant shared that "having the confidence [to be active] has been really huge and still something I am working on" (P01). Another shared her perspective:

"I think I need to work on being more problem solving oriented rather than seeing the barrier and thinking oh ok it's not going to work... I think that it is about problem solving umm. Realizing that ok, there is this barrier, and then thinking of way to, to think outside of the box of ways, of solutions for it. Instead of seeing it as an unscalable wall, like can I walk around it? Ya, trying to climb over it" (P02).

Many participants shared how their perceptions of activity and wellness changed over the course of the program. A young participant with described:

"my view of what it means to be active is completely different than it was before. So before being active meant going for a swim or going for a long walk,... going to the gym, going for a workout, going doing yoga. Those were always associated with being physically active... I guess I wouldn't have thought going to be the mailbox being physically active, I wouldn't have considered going... So now I have, my mind set has changed, so that I know that, I know that I

can still be physically active based on my current abilities, and it might look different than what I thought of before. But it does not matter, I am still being active” (P01).

Challenges and Triumphs

This subtheme includes descriptions of the ups and downs participants encountered over the course of the program. Some participants acknowledged that it was challenging to change their activity behavior. Many knew of the benefits of interrupting their sitting and of moving more throughout the day, but found it challenging to incorporate in their daily lives due to physical and cognitive barriers. An older participant shared her experience:

"I understand that it is important for me not to sit all day long and play on the computer... You guys really underlined that, so that was really important for me to learn, I wouldn't have learned it otherwise I don't think... So, I have that firmly embedded in my head, but my legs have not quite gotten the message" (P03).

Participants with comorbidity and greater mobility impairment expressed the same desire to be active, but they talked about physical symptoms as a barrier to activity. A participant stated that “a lot of patients do want to be doing this stuff like getting up and moving around a lot more. It's not being lazy, it's just them not being able to do it” (P06).

Despite some challenges, several participants described how they felt better when being active in their daily lives. One participant described how an increase in confidence was key to her feeling better and being active. She said that "I have had a couple falls beforehand and I was unsteady on my feet and just fatigue and stuff like that was causing me, was giving me confidence issues. So now that I feel better about myself and I am more fit, I can get around easier and it's kind of feeds on itself" (P05).

Many participants perceived that there were psychological benefits to moving more. One participant shared how she recognized that activity had an impact on how she was feeling. She shared that "I think just realizing how much moving does play a role in how I feel... If I can move as much as I can, without overdoing it, then I will feel better" (P02). Another participant described that “even if I don't physically feel better, I mentally feel better because I have accomplished something” (P07).

Some participants described how they have experienced benefits of moving more throughout the day and that they are excited to be more active in their daily lives. A participant shared her perspective:

"I have seen firsthand the benefits. So, it's one thing to sit all day and go to the gym, and to do an hour and a half hour workout afterward. But that's totally different. The benefits are totally different than the interspersing of bouts of less intense and more frequent activity during the day. It reduces the soreness and the fatigue, the heaviness in the muscles isn't there when I get up more often" (P10).

Another young participant shared her experience:

"I think the biggest thing for me is that I am excited about moving, excited about physical activity because I know it feels good and it's helping me, and it increases my energy and I just feel better. So I think that is a big turnaround where I had been like a year and a half of not doing much to now I am doing more things, and it feels good" (P01).

Beginning of a Wellness Journey

This subtheme includes descriptions of the participants' goals and increased daily activity as a journey, and their intentions to be active in the future. Many participants shared how this program was the beginning of their wellness journey and that they will continue to improve certain aspects of their activity to achieve their goals. A participant described her experience:

"I think the program really helped me in that journey... I think I still have a lot of work and growth to do but umm but it definitely showed me that I can do more than I thought I could... I think I believed that I was where I was and I wasn't going to improve, that I was just going to have to learn how to live with it. Umm so it surprised me in that way. I wasn't expecting umm to improve so much... It completely changed my life" (P02).

Participants also recognized that their wellness journey will continue after the program. All participants described intentions to be more active after the program. Participants perceived that goal setting and self-monitoring were key to maintaining their level of activity. A participant shared that "the goal portion, like of the self-efficacy stuff that you taught us, is super important for continuing to maintain this type of stuff, like moving, to maintain that, those sitting goals for the future, to like keep doing it in your life" (P01). One participant described how she intends to continue being active, but realizes that her goals may have to be adjusted in the future. She shared that "my goal is to continue on with this. And like I said with minor adjustments as the years go but I definitely intend to keep this up. It's got to be something that you decide to do. It's part of

your day just like brushing your teeth, you know what I mean, or having a shower like it's gonna be part of your routine” (P09).

Some participants described how they had goals to integrate into community based programs. A participant shared her experience:

“I have goals and a plan that I am going to implement, getting back to the pool to aquacises, those sorts of things... I will pursue what there is in my community and I will find what there is for umm exercise classes. I tend to be the type of person that is more likely to follow through if I am involved in an exercise class... That’s all a part of knowing I need to keep pushing myself and keep working to remain active” (P08).

Several participants described how self-monitoring would be a key to maintaining their level of activity. One participant shared her perspective:

“now that I have set some goals and realized they are attainable, I’m going to continue to monitor myself, if not every day for the rest of my life but intermittently you know say next year I’ll wear the Fitbit™ for a month here and a month there just to make sure that I’m staying up to the same level and if not start analyzing my situation and just like with the program that I went through with (the interventionist). Why am I not being active? What can I do to improve? Do I need to find things that are more interesting to me? Do I need to find things that fit my abilities better? Like I’ve got an understanding now of what I need to do to pick it up again if I should fall off” (P10).

A participant also described how she will adapt her activity monitoring device to make it more convenient for her. She shared:

“I am thinking of upgrading my Fitbit™ to one that says heart rate... It’s easier to keep on. Because I found that the One™ sometimes umm it’s easy to lose, not lose but misplace. And sometimes I go swimming, and you can’t take it swimming, and one of my favorite activities is swimming. So that’s a big chunk of my activity especially over the summer where we were spending like five hours in the water at a time” (P05).

Participant reflections on the results

Four out of ten participants responded to the member reflections and perceived that the results captured their perspectives of the *Sit Less with MS* program. The themes of increasing activity awareness and accountability, as well as making small, meaningful steps towards their goals participants resonated with all participants who completed the member check. A participant also commented that she wished that this type of program was available in the community after the study’s completion as she would benefit from ongoing support to maintain the changes to her activity behavior.

Discussion

This is the first qualitative study exploring the perceptions of adults with MS in a sedentary behaviour change program delivered over a telerehabilitation medium. The participants perceived that they could be active in everyday life, that the program provided key elements to experiencing success and was a wellness journey. These perceptions reflect that participants recognized the importance of the “sit less and move more” message and developed strategies to continue interrupting their sitting time and to remain active in the future.

Being active in everyday life embodied itself differently for every participant. As an interventionist, I perceived that participants were open to exploring different strategies to sit less and move more throughout the day. For many participants, it was a process of trial and error to find strategies to experience success sitting less and moving more throughout the day. The strategies that participants chose were often ones that increased their confidence to be active and that could be easily adjusted in response to changes in their schedule or symptoms. Some common strategies included walking around the living room coffee table during TV commercials, taking shorter but more frequent walks in their neighbourhood and walking in their home while waiting for a load of laundry to finish. This finding suggests that participants can learn and experience success implementing strategies to interrupt their sitting and increase their daily activity by participating in a telerehabilitation delivered sedentary behaviour change program. These perceptions are different than those of participants with mobility impairments in other physical behaviour change programs that described that they had difficulty adhering to physical activity programs as a result of barriers.⁶⁰ A participant experiencing success applying strategies to sit less and move more in their normal, everyday lives may be a key to long-term adherence to sedentary behaviour change.

Participants described elements of the program which were key to experiencing success. These included becoming aware of and accountable for their activity, taking small, meaningful steps towards their goals, and participating in an Internet-based program. These results are similar to the perceptions of adults with chronic disease and mobility impairments in other telehealth^{135,136} and physical activity programs.⁶⁰ Learning to become aware and accountable of their activity, and developing goal setting and self-monitoring skills were key for success.^{60,135,136} These skills and strategies increased the participants’ confidence to continue being active despite setbacks and

promoted long term engagement in physical activity.⁶⁰ In other telerehabilitation studies, some participants did not describe self-monitoring in a positive light⁶⁰ as they felt that “big brother” was watching their activity.²¹ In the *Sit Less with MS* program, although no participant commented on being over monitored, some voiced frustrations and demotivation as the FitbitTM was not recording their steps. As an interventionist, I perceived that participants with greater mobility disability and slower gait speeds experienced more problems related to step recording. This is a known problem with commercial-grade physical activity monitors, such as the FitbitTM. A publication by Hergenroeder et al. (2019) highlighted that devices undercount steps by more than 50% in adults ambulating at slower gait speeds (<0.8 m/s).¹³⁷ Only one monitor, the Accusplit Accelerometer Pedometer, was highly accurate in reporting step counts in individuals who walked at least 0.8 m/s. Given the high accuracy of step counts at low gait speed and low cost, the Accusplit may be more appropriate for adults with slow gait speed compared to the FitbitTM.¹³⁷ These findings suggest that activity monitoring devices should be used as a tool to monitor change in daily activity and sitting interruptions and not be the central focus of the program. Interventionists should also be cautious not to over emphasise the reporting of activity monitoring data during coaching sessions. In addition, many participants suggested that future activity monitoring devices should also record the number of sit to stand interruptions per day.

Although there were some frustrations with the use of technology, participants described that if it was not for the Internet-based medium, they would not have been able to participate in the program. This highlights that delivering a program via an Internet-based medium eliminates barriers to participation and increases the program’s accessibility for individuals with MS. These perceptions were echoed by adults with MS participating in an Internet-based physiotherapy program as they perceived that the program increased flexibility, eliminated transportation barriers and required less energy compared to attending sessions at a local center.¹¹¹ Participants with chronic disease and mobility impairments in Internet-based programs also described an overall positive experience and highlighted that the program’s convenience was the most notable feature.^{60,111,136,138,139} Communication via an Internet-based medium allowed participants to foster a positive therapeutic relationship with the professional^{60,135,136,138,139} while increasing levels of activity and function, and promoting wellbeing.¹³⁸ In future programs, participants should be encouraged to communicate over a video-conferencing medium, such as FaceTimeTM or SkypeTM,

compared to the phone to allow both the participant and coach or clinician to see each other, fostering a more natural therapeutic relationship.

While all participants in this study preferred the Internet-based medium compared to attending in-person sessions, some adults with chronic diseases and mobility impairments in other Internet-based physical activity programs described that receiving a program via an Internet-based medium did not replace face-to-face interaction.^{136,138,139} This may have been a result of difficulty of using the Internet-based medium^{60,136,138,139} due to less familiarity with technology.¹¹¹ Adults with MS may experience more success receiving a program via telerehabilitation as they are younger⁹⁹ and high Internet users¹⁰⁰ compared to other adults with chronic conditions. These characteristics may also decrease the learning curve to engaging in a telerehabilitation program.

The participants' perceptions of self, activity and wellness changed during the *Sit Less with MS* program. These changes were also perceived by other adults with mobility impairments participating in physical activity programs.⁶⁰ Participants in other studies⁶⁰ described positive changes in self-perception and understood the importance of remaining active. This led to participants developing and embodying a new physically active identity. Physical activity was also reframed as being fun and rewarding as well as a priority in participants' lives.⁶⁰ These findings call attention to the central role of changing perceptions in a behavior change program. This may suggest that changing health beliefs is necessary for long term behaviour change, as described by the Health Belief Model.¹⁴⁰ In addition, participants in this study believed that they could sustain their level of activity in the future. However, we do not have any evidence that they continued to interrupt their sedentary behaviour and increase their activity throughout the day. Participants should complete objective measures, such as the 6 Minute Walk Test¹⁴¹ and the Short Physical Performance Battery¹⁴², and be interviewed six to twelve-months post intervention⁸³ to increase our understanding of long-term maintenance of behaviour change.

Participants in this study did not describe negative perceptions of activity that limited their intentions to change their sedentary behaviour. This perspective differs from some adults with mobility impairments in physical activity program who described feeling that their symptoms were worsening as a result of increased activity and that physical deterioration was inevitable.⁶⁰ Participants in our study may have had more positive perceptions of activity as they experienced success achieving their goals, learned strategies to slowly increase their daily activity without

exacerbating their symptoms as well as experienced physical and psychological benefits to interrupting their sitting throughout the day.

The perspectives described in this study are applicable to adults with MS with mild to moderate mobility disability participating in a telerehabilitation sedentary behaviour change program. Due to time and feasibility restrictions, it was not possible to interview all participants in the *Sit Less with MS* program. Although the authors were conscious to recruit participants with a range of characteristics to increase the depth of perspectives, including more individuals in the study may have highlighted different perspectives of the Internet-based program. Given that this is the first study investigating the perspectives of adults with MS in a telerehabilitation sedentary behaviour change program and that participants were recruited from one program, there are many future areas of research that can be explored. Some of these include describing the participants' experience adhering to the changes in their sedentary behaviour six to twelve months after the completion of the program, exploring how beliefs of self, activity and wellness impact an individual's adherence of sedentary behaviour change, and designing programs providing ongoing support for behaviour change via telerehabilitation.

This study provides new insights into the experience of adults with MS participating in a telerehabilitation sedentary behaviour change program, including that participants experienced success sitting less and moving more in their daily lives and that participants were able to differentiate between the benefits and messaging of "sit less and move more" compared to increasing levels of physical activity and aerobic exercise. This study also highlights important implications for clinicians working with adults with MS and other neurological conditions in a rehabilitation setting, such as being open to using telerehabilitation as a tool to provide therapy services and discussing the benefits of decreasing sedentary behavior with clients.

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Declaration of interest statements

Two authors in this study (J. R. and D. G.) were interventionists in the *Sit Less with MS* program. T. M. was the primary researcher in the development of the *Sit Less with MS* program.

Chapter 4: Conclusions and Clinical Applications

This is the first qualitative study exploring the perceptions of adults with MS in a sedentary behaviour change program delivered over a telerehabilitation medium. In this conclusions chapter, I will explore the application of future home-based sedentary behaviour programs, the use of telerehabilitation in clinical practice and strategies to increase education about sedentary behaviour in neurological rehabilitation. I will also describe perspectives as an interventionist in the *Sit Less with MS* program and how they relate to the development of future sedentary behaviour change programs.

Home-Based Sedentary Behaviour Change Programs

The participants' perceptions support the delivery of a home-based sedentary behaviour change program through a telerehabilitation medium. Participants understood the difference between the message of "sitting less and moving more" compared to simply increasing physical activity. They were also able to describe the benefits of interrupting their sitting behaviour and incorporating more light physical activity during the day. Participants learned strategies to sit less and move more in their daily lives. Our findings suggest that the *Sit Less with MS*'s novel program design may increase long term adherence to activity behaviour change compared to physical activity programs. Nevertheless, further research is necessary to investigate participants' long term adherence to changes in sedentary behaviour.

Application of Telerehabilitation in Neurological Populations

All study participants were satisfied with telerehabilitation as the mode of delivery as it removed barriers to traditional rehabilitation services, such as increased time and cost of face-to-face therapy.¹⁴³ Given the positive perspectives of telerehabilitation in our study, adults with MS may have high levels of engagement and satisfaction with other telerehabilitation services in the future. High levels of satisfaction with have been reported amongst adults with neuromusculoskeletal¹⁴⁴⁻¹⁴⁶ and neurological conditions¹⁴⁷ receiving physiotherapy interventions over telerehabilitation compared to face-to-face therapy.

While telerehabilitation may never replace face-to-face therapy in the neurological population due to complex assessment and interventions needs, such as advanced standing balance and practicing vertical transfers, telerehabilitation could be used as a tool for follow up and maintenance after a period of therapeutic intervention. Recent work by Dr. Lovo Grona provides an example of the application of telerehabilitation and video technology to augment physical therapy treatments in rural communities. The remote presence robot (RPR) allows clinicians to complete comprehensive neuromusculoskeletal examinations and facilitate patient education via video technology and screen sharing features. The RPR allows the multidisciplinary team to provide comprehensive assessments, build rapport and provide education with a high level of patient satisfaction.¹⁴⁸ As the use of telerehabilitation and related technologies, such as the RPR, continues to be explored in physical therapy, we need to ensure that both patients and clinicians perceive that the medium of delivery are useful and easy to use. The accessibility and ease of use of future telerehabilitation programs can be evaluated using the Technology Acceptance Model.¹⁴⁹ This study provides preliminary evidence for the acceptance of a sedentary behaviour change program delivered over a telerehabilitation medium. Future randomized control trials should evaluate programs' accessibility and ease of use using the Technology Acceptance Model¹⁴⁹.

Furthermore, with the increased use and acceptance of telehealth, governing bodies are developing policies to guide the delivery of telehealth services. For example, Physiotherapy Alberta has published policies to ensure that physical therapists have the competences to provide high quality assessments and therapy sessions over a telerehabilitation medium.¹⁵⁰ These policies outline that physical therapists should use their clinical skills to determine if it is appropriate to provide therapy over an Internet-based medium, have the competencies to deliver telerehabilitation, such as familiarity using technology, and complete ongoing competence and service development, such as recording patient outcomes and satisfaction.¹⁵⁰ Physical therapists currently provide telerehabilitation to clients with neurological conditions, including stroke^{147,151}, spinal cord injury^{152,153}, and Parkinson's disease.^{154,155}

Increasing Sedentary Behaviour Education in Neurological Populations

Several physical activity guidelines have been developed for adults with neurological conditions.^{110,156–158} Although there are benefits to increasing physical activity, including increasing strength^{156,158} and decreasing the risk of cardiovascular events¹⁵⁸, many adults with chronic disease and mobility impairments have described barriers to accessing traditional physical activity services, such as increased distance to the service location, limited transportation and insurance coverage.^{33,159} In addition to providing education regarding the benefits of physical activity, clinicians should discuss the risks of increased sedentary behaviour, such as comorbidity⁶², and provide education on strategies to sit less and move more with clients, such as goal setting, self-monitoring, self-efficacy as well as barriers and facilitators to sitting less throughout the day. Providing patients with activity monitors, such as the FitbitTM or ActivPALTM, is key to increasing activity awareness and teaching clients how to self-monitor their activity to achieve their goals. A focus on decreasing sedentary behaviour may be more feasible for adults with neurological disease to integrate into their daily lives rather compared to adhering to aerobic and strength training guidelines.^{110,156–158}

Interventionist Perspectives

As an interventionist for the *Sit Less with MS* program, I have a unique perspective on coaching adults with MS in a telerehabilitation program. Many participants shared that they would like telerehabilitation programs to be available in the community and would sign up to participate in a similar program in the future. This suggests that adults with MS may have high levels of engagement and satisfaction in future telerehabilitation programs.

While most participants did not experience difficulties using the technology, some participants required more teaching and technology support. The majority of participants in the *Sit Less with MS* program were able to follow multistep commands over a video-conferencing medium or phone to set up and view their FitbitTM data. Face-to-face troubleshooting sessions were organized with participants who experienced greater cognitive impairments or had very limited familiarity with technology. These sessions were often organized two to three weeks into the program after many attempts at troubleshooting over the video conferencing medium or phone. In the future, screening for familiarity with technology could be completed over the phone prior to the participant's baseline assessment. If participant scores low on the technology familiarity

screen, an interventionist could be present at the baseline assessment to provide a short, in-person Fitbit™ familiarization.

My colleagues and I who were interventionists in the *Sit Less with MS* program also perceived that coaching sessions delivered over a video-conferencing medium flowed better compared to those provided over the phone. In addition, the most important skills of an interventionist included active listening and being a good communication. Video-conferencing coaching sessions may have flowed better given that the participant's expression and non-verbal language cues could help the interventionist guide the topics and questions during the coaching sessions. In addition, having the ability to see the participant during technology troubleshooting sessions increased efficiency while decreasing the participants' frustration by resolving technical problems more effectively. Although some participants were hesitant to complete the coaching sessions over a video-conferencing medium, we perceived that participants who chose to complete the chats over FaceTime™ or Skype™ were more engaged during the coaching sessions compared to those who completed the sessions over the phone. In future programs, any individuals with good active listening and communication skills could be trained as an interventionist. Although a clinician should be present at baseline and follow up assessments to complete standardized testing, it is not necessary for clinicians to complete the weekly coaching sessions.

This thesis provides many insights into the clinical application of telerehabilitation in the MS community. As a physical therapist working in neurological rehabilitation, I would encourage my colleagues to consider using telerehabilitation as a tool to provide physical therapy services and to begin more discussions about the benefits of decreasing sedentary behavior with clients. Providing physical therapy to individuals with neurological diseases in remote and rural communities is a challenge^{17,160} and telerehabilitation has the potential to fill this gap.^{17,160}

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Appendices

Appendix 1: Interview Guide

General changes during the program

Can you tell me about what you feel has changed over the course of the program?

Weekly coaching sessions

Now let's talk about the weekly coaching sessions.

- How did they go?
- What did you like about them?
- What things could be improved?
- What did you think of receiving a weekly newsletter?
- What did you think about talking to your coach through Skype/phone?
- One of the topics that was discussed with the interventionist was goal setting.
 - o Tell me how you think you'll apply what you've learned about goal setting in the future.
- During weekly chats, you also reviewed your activity using the Fitbit. How did it go?
- A few times during the program you also reviewed your ActivPAL report. How did it go?
- During the program, you discussed some challenges to being active and some things that may help you stay active.
 - o Could you tell me about some of the challenges you experienced to be active?
 - o Tell me about some things that helped you stay active.

Changes in physical activity beliefs

- Now that the program is complete, how would you say your way of thinking about being active throughout the day has changed?
- What does it mean to you to sit less?
- What does it mean to you to move more?

Intentions to continue to engage in physical activity

- Now that the program is complete, how do you intend to continue being active?
- How confident are you about staying active now that the program is complete?

Close

- If you were to describe your experience with the Sit Less with MS program to someone else, what would you tell them?
- If the MS Society of Canada said they would offer this program, what are two things that you would say need to change?
- Anything else you'd like to chat about related to your experience with the Sit Less with MS program?

Appendix 2: Member Reflections

Thank you for participating in the interview portion of the Sit Less with MS program. That's the portion of the study whose goal was to try to get an in depth understanding of your perspectives on the program. Now that interviews with 10 participants are complete, we invite you to share your thoughts on the results to date. A reminder that the results of this type of study (i.e., with interviews) are generally a written description of 3-5 themes, or things we heard consistently from various people.

The purpose of this short survey is to get your impressions of the results. I have presented the research findings in the table below. The table includes the name of the themes and then how they were defined.

We would appreciate your thoughts! You could fill in your feedback below in the survey or if you feel more comfortable providing your perspective of the results over the phone, we can schedule a time to call.

Thank you very much.

		Definition
Theme 1	Being active in normal, everyday life	Descriptions of how participants perceived they could be active in normal, everyday life.
Theme 2	Key elements to experiencing success <ul style="list-style-type: none"> • Awareness of activity • Accountability • Internet-based medium • Small, meaningful steps towards goal 	<p>Descriptions of what participants thought were key elements to experiencing success during the program.</p> <p>Descriptions of how participants perceived their awareness of activity changed during the program.</p> <p>Descriptions of program elements that participants perceived increased their accountability to their activity goals.</p> <p>Descriptions of how participants perceived that the Internet-based medium increased the accessibility of the program and allowed them to participate.</p> <p>Descriptions of how participants experienced success through small, meaningful steps towards their goal.</p>
Theme 3	Wellness journey <ul style="list-style-type: none"> • Change in perspective • Challenges and triumphs • Beginning of a wellness journey and intentions to be active 	<p>Descriptions of how the participants perceived that their perspectives towards themselves, activity and wellness changed, that they experienced challenges and triumphs over the course of the program and that the program was the beginning of their wellness journey.</p> <p>Descriptions of how the participants perceived that their perspectives towards themselves, activity and wellness changed.</p> <p>Descriptions of the ups and downs participants encountered over the course of the program.</p> <p>Descriptions of the participants' evolution of mind-set, goals and daily activity as a journey and intentions to be active in the future.</p>

- Do the themes in the Table reasonably capture your perspectives on participation in the Sit Less with MS program? Please explain.
- Is there one or two things in particular that resonate with you, regarding the results? Things that you thought - "Ahh, that's exactly what I thought". Please explain.
- Was there anything in the themes that you thought did not make sense? Please explain.

Link:

https://docs.google.com/forms/d/e/1FAIpQLSencGCTsrsNNJmouluNrEbp4X27FhIxdM6ZqlG_HzsITKYbvA/viewform?usp=sf_link

Appendix 3: University of Alberta - Ethics

INFORMATION LETTER

Title: Reducing sedentary behaviour: A novel opportunity for managing comorbidity in MS?

Research Investigator:

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Background

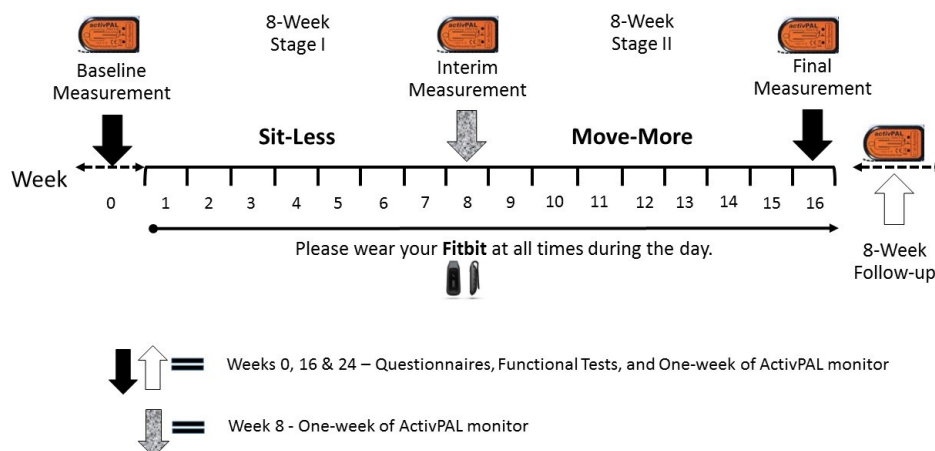
We invite you to participate in a research project. We are developing and testing a program for adults with multiple sclerosis (MS). The program is designed to help you to interrupt and reduce your sitting time and replace it with light activities. Increasing activity may help you to manage your MS symptoms such as fatigue or pain.

Purpose

The purpose of this project is to determine the feasibility of a sedentary behaviour program for improving activity outcomes and co-morbidities such as walking disability and fatigue.

Program Procedures

The **diagram below** provides information about what we'll be doing. If you decide to participate, we will ask you to come to the University of Alberta campus (Corbett Hall, 8205 114 Street) three times. These visits to Corbett are indicated by arrows – we ask that you come once before the program starts, after the program finishes at 16 weeks, and then 8 weeks later. The arrow in the middle (at interim) does not involve a trip to Corbett.



Your involvement in this project will be 24 weeks in total. The actual program duration is 16 weeks and is divided into two stages: Stage I (Sit Less), and Stage II (Move more), as indicated on the diagram. When we see you the first time, we will measure your weight and height and ask you to answer a few questions about yourself (e.g., age), your MS (e.g., how long since you were diagnosed), and your medications. You will then complete several questionnaires including ones about fatigue, pain, cognition, sleep, and physical activity. There are also some walking tests. These measurements will take about two hours. We repeat all these measurements two more times; at final (Week 16), and follow-up (Week 24).

You will also wear the small device below (ActivPAL monitor) at four measurement points: baseline (Week 0), interim (Week 8), final (Week 16), and follow-up (Week 24). It will be worn at all times for **7 days, each time**. The ActivPAL (see picture below) is worn on your right thigh and covered up with non-allergenic waterproof tape. The ActivPal measures your sitting, standing and walking time, and step counts. Once the program starts (week 1 on the diagram), you will be asked to wear a Fitbit. You will be taught how to use it to track your activity. We will ask you to wear the FitBit at all times when you're awake, for the 16 weeks of the program. We will ask you to complete a log book to record your bed-time and sleep-time.



ActivPAL3™ monitor



Fitbit

The program involves weekly chats with a coach (via skype or the phone). Each week, we will send you a 2-page newsletter to read. These newsletters will help guide our weekly discussions. At the end of the program, you will complete a short (15-20 question) survey about your experiences participating in the program. Some of the participants (6-10) complete an interview. These interviews are part of a related study with the goal to understand your experience participating in the program in greater depth than from a survey. We will audio record the interview, and transcribe it word for word.

Benefits

- The information we collect from this research will be used to test the internet-based SitLess with MS program. There are NO COSTS to participation. At the end of the program, you will keep the Fitbit as a token of our appreciation.
- If you come with your car, during the trips to Corbett we will provide you a parking pass. If you use DATs we will cover the cost of DATS during your trips to Corbett.
- By participating and providing feedback on the program, you will help to ensure that the program is fully applicable to you and others with MS.

Risk

- There is minimal risk associated with participating. If you feel uncomfortable with any stage of the program, you can choose not to participate or answer the question and ask the assessor to move onto the next stage. During all assessments, you can take a rest at any time you wish.

Voluntary Participation

- You are under no obligation to participate in this program. The participation is completely voluntary.
- You can opt out of the program without penalty. Even if you agree to be in the program, you can change your mind and withdraw at any time. In the event of opting out in the middle of the interview, we will erase your interview.

Confidentiality & Anonymity

- Information we collect from you will be anonymous. Participants will not be identified in the dissemination of the research.
- The data (including audio files and transcripts) will be kept confidential. Only the primary researchers (Manns, Motl) and selected staff or graduate students they supervise will have access to the data.
- Data will be kept in a secure place for a minimum of 5 years following completion of the research project. Electronic data is password protected.
- If you would like to receive a copy of the final report from this research project, please make us aware of that by leaving your email address.

Further Information

- If you have any further questions regarding this project, please do not hesitate to contact Trish Manns (trish.manns@ualberta.ca) or Saeideh Aminian at 780-492-8968, saeideh@ualberta.ca
- The plan for this project has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

Participant ID:**CONSENT****Title:** Reducing sedentary behaviour: A novel opportunity for managing comorbidity in MS?**Principal Investigator(s): Dr. Patricia Manns****Phone Number(s): 780.492.7274****Co-Principal Investigator: Dr. Robert Motl****Phone Number(s): 205.934.7787**

	Yes	No
Do you understand that you have been asked to be in a research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you read and received a copy of the attached Information Sheet?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand the benefits and risks involved in taking part in this research study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand the post-intervention interview will be audio recorded?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had an opportunity to ask questions and discuss this study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you are free to leave the study at any time, without having to give a reason and without any penalty?	<input type="checkbox"/>	<input type="checkbox"/>
Has the issue of confidentiality been explained to you?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand who will have access to your study records?	<input type="checkbox"/>	<input type="checkbox"/>
Who explained this study to you? _____		
I agree to take part in this study:		
Signature of Research Participant _____		
(Printed Name) _____		
Date: _____		
I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.		
Signature of Investigator or Designee _____ Date _____		
THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT		

Saeideh Aminian, PhD**Post-Doctoral Fellow**

Phone: 780-492-8968

Email: saeideh@ualberta.ca

Appendix 4: File Management

All files from this research study will be saved on the *University of Alberta R-Drive –TM RESEARCH – MS Novartis Project 2016-2018 – Jacqueline Rowley*.

Saving audio-recordings to the R-Drive

Under the *Audio-recording* file, each interview audio-recording will be saved as:

IPA Qualitative Research – SLwMS – Audio-recording - [Participant number] – [Date of interview]

Ex. IPA Qualitative Research – SLwMS – Audio-recording - 01 – May 04, 2018

Saving interviewer notes to the R-Drive

Under the *Interview notes* file, each interview notes document will be saved as:

IPA Qualitative Research – SLwMS – Interviewer notes - [Participant number] – [Date of interview]

Ex. IPA Qualitative Research – SLwMS – Interviewer notes - 01 – May 04, 2018

Saving interview transcripts to the R-Drive

Under the *Interview transcripts* file, each interview notes document will be saved as:

IPA Qualitative Research – SLwMS – Interviewer transcript - [Participant number] – [Date of interview]

Ex. IPA Qualitative Research – SLwMS – Interviewer transcript - 01 – May 04, 2018

Saving NVivo notes to the R-Drive

Under the *Interview NVivo notes* file, each interview notes document will be saved as:

IPA Qualitative Research – SLwMS – Interviewer NVivo notes - [Participant number] – [Date of interview]

Ex. IPA Qualitative Research – SLwMS – Interviewer NVivo notes - 01 – May 04, 2018