

Targeting Physical Activity Behaviour Change in the Management of Multiple Sclerosis

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ABSTRACT

Purpose: The purpose of this thesis is to investigate how physical activity behaviour can be optimized in routine care for persons living with multiple sclerosis in Saskatchewan. Physical activity is an important behavioural intervention in the management of multiple sclerosis; however, persons living with multiple sclerosis are far less active than needed to accrue health benefits. We aimed to explore the local context from the perspectives of key end-users (persons living with multiple sclerosis and health care providers), as a starting point to address this disconnect between evidence on physical activity and rates of participation.

Methods: Three studies were conducted as part of this manuscript style thesis.

Study 1 used Interpretive Description, a qualitative research methodology to investigate health care providers' current practices and perspectives regarding physical activity behavioural interventions in the management of multiple sclerosis. Focus groups were conducted with 31 multi-disciplinary health care providers in Saskatchewan working with individuals living with multiple sclerosis.

Study 2 also used Interpretive Description to explore the perspectives of persons living with multiple sclerosis with regards to their priorities and proposed solutions for optimizing physical activity behaviour in the management of multiple sclerosis. Focus groups were conducted with 24 individuals living with multiple sclerosis in Saskatchewan.

For both Study 1 and 2 inductive thematic analysis, triangulation and member checking were applied in data analysis. Data were coded individually by three researchers, who then collaboratively developed themes.

Building on key findings from Study 1 and 2, Study 3 was a systematic review conducted using the Preferred Reporting Items for Systematic Reviews and Meta-analyses guidelines. Study 3's objective was to identify and synthesize the existing literature that describes methods used to train health care providers to deliver behaviour change strategies for physical activity interventions in neurological populations, including multiple sclerosis.

Results: This preliminary research showed that physical activity behaviour is not currently being targeted in routine management of multiple sclerosis in Saskatchewan. Persons living with multiple sclerosis want support from their health care providers regarding physical activity behaviour change. Health care providers believe physical activity is important, but they are not currently prioritizing it in practice. Physical activity as a management strategy does not exist in isolation. Findings suggest the problem is greater than just low physical activity levels – care needs to be improved. Individual and systems level change are needed. Essential components hypothesized to optimize physical activity behaviour in the management of MS found in this thesis include support, training, model of care and communication. Both health care providers and persons living with multiple sclerosis suggested the need to address individual level change through increasing the use of behaviour change strategies.

Training health care providers on behaviour change strategies is one approach at the individual level to improve physical activity behaviour change in multiple sclerosis. Based on our systematic review, there is currently insufficient evidence for consensus on what should be included in and how to structure training for HCP to increase ability, confidence and use of BCS for PA with neurological populations. With a growing number of studies showing effectiveness of BCS to increase PA in neurological populations, there is a need for future work to highlight the most important strategies as well as how to best implement their use into clinical practice.

Conclusion and Significance: This PhD research is a starting point to help improve health care providers and persons living with multiple sclerosis knowledge, use and ultimately change in physical activity behaviour. The findings of this thesis show that future efforts (both research and interventions) need to acknowledge that there are barriers to utilizing PA behaviour change for PwMS at several levels (individual, health care system, community and policy), and work is needed at each of these levels in order to implement change. Taking an integrated knowledge translation approach to further the next steps in research is recommended to promote concurrent and complimentary change needed. Future efforts should target the key factors of support, training, model of care and communication found in this thesis to address localized priorities, to maximize potential applicability to end-users and to effect meaningful change.

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DEDICATION

To: 1) The process of inquiry (and persistence...); and
2) All the weird and wonderful reasons I ended up in Saskatchewan.

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LIST OF ABBREVIATIONS

BCI	behaviour change intervention
BCIs	behaviour change interventions
BCS	behaviour change strategies
BCTTv1	Behavior Change Technique Taxonomy version 1
CNS	central nervous system
DMT	disease-modifying therapy
DMTs	disease-modifying therapies
HCP	health care providers
ICF	International Classification of Functioning, Disability and Health
ID	Interpretive Description
iKT	integrated knowledge translation
MRI	magnetic resonance imaging
MS	multiple sclerosis
P	participant
PA	physical activity
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-analyses
PT	physiotherapist
PTs	physiotherapists
PwMS	persons living with multiple sclerosis
OT	occupational therapist
OTs	occupational therapists
RRMS	relapse remitting multiple sclerosis
SCT	Social Cognitive Theory
SK	Saskatchewan
WIDER	Workgroup for Intervention Development and Evaluation Research

CHAPTER 1: Introduction and Literature Review

This chapter will present the research objectives, purpose and rationale for this doctoral thesis. Further, an overview of relevant background information, state of the literature, methodology, and context for the following chapters will be included.

1.1 Problem statement, Purpose and Objectives of Thesis

Persons living with multiple sclerosis (PwMS) are far less active than needed to accrue numerous benefits that have been reported to influence symptom severity, fitness, disease progression, function and risk of co-morbidities. Furthermore, although behavioural interventions are a recommended method for successful promotion of physical activity (PA) participation with PwMS, behavioural interventions to address PA are not a regular component of routine care. The purpose of this thesis is to investigate how PA behaviour can be optimized in the routine management for PwMS in Saskatchewan (SK). To achieve this goal, three manuscripts will address the following objectives:

- 1) To investigate the current practices and perspectives of HCP regarding PA behavioural interventions in the management of MS
- 2) To explore the perspectives of PwMS with regards to their priorities and proposed solutions for optimizing PA behaviour in the management of MS, and
- 3) To identify and synthesize the existing literature that describes methods used to train HCP to deliver behaviour change strategies (BCS) for PA interventions in neurological populations, including MS.

1.2 Background information on Multiple Sclerosis: Description, Prevalence and Health Impact

Multiple Sclerosis (MS) is a chronic progressive neurodegenerative disease primarily affecting the central nervous system (CNS - brain and spinal cord).¹ MS pathology is characterized by inflammation, demyelination, reactive gliosis and neuroaxonal damage.² The cause is currently unknown, but MS occurs in people with a genetic susceptibility triggered by an environmental or viral event and is thought to be related to an auto-immune process.³ Females are more affected than males (roughly a 3:1 ratio) and MS is seen more in areas further from the equator.⁴ MS is the most common cause of neurological disease among young adults, typically diagnosed between 20 to 40 years of age.⁵ An estimated 77,000 Canadians are

living with MS and approximately 2 million people worldwide.⁶ SK has among the highest rate of MS in the world with a recent prevalence estimated at 315 per 100,000 people.⁷

At initial MS diagnosis a person will have either a 'primary progressive' or 'relapse-remitting' (RRMS) disease course. Roughly 85% start with RRMS, which includes periods of relapses (episodes of neurological dysfunction lasting longer than 24 hours) and recovery (extent to which is variable and may be incomplete).^{1,8} Within 10 years of being diagnosed about 50% of individuals with RRMS will go on to develop a progressive stage transitioning into a 'secondary progressive' disease course.^{1,8,9} Historically, by 25 years post diagnosis 90% of individuals with RRMS go on to develop a progressive form of MS called secondary progressive; however, this percentage is potentially decreasing with the development of new medication.⁹ The progressive forms (both primary and secondary) of the disease are characterized by more steady progression of neurological damage and clinical symptoms, with or without relapses and minor plateaus.¹⁰ The damage caused by MS and its location within the nervous system manifests as a loss of physical and psychological function, progressive symptoms and an overall reduction in quality of life.¹ The resulting disability is unpredictable with significant variability in symptoms and severity overtime. MS is a markedly heterogeneous disease full of uncertainty and unpredictability. Not only is there variability in what part of the nervous system is affected, there is variability in the severity of resulting symptoms overtime, as well as fluctuations within an individual in the absence of relapse.

PwMS experience a variety of neurological symptoms and a variable loss of function. Impairments due to neurological damage can include paresis, spasticity, sensory, balance, coordination, fatigue, vision, bowel, bladder and sexual dysfunction, as well as deficits in cognition and mood.¹ Across the MS spectrum the top five patient reported impairments are gait, balance, fatigue, paresthesia and weakness.¹¹ Based on current data from a Swiss study (n=855) the most commonly reported symptoms in progressive MS were gait, balance, fatigue, paresthesia, spasticity, bladder problems and weakness (reported in 90% of sample, 84%, 83%, 80%, 79%, 75% and 71% respectively).¹¹ For those living with RRMS paresthesia, fatigue, weakness, balance, memory, gait and pain were most common (reported in 77% of participants with RRMS, 74%, 55%, 51%, 48%, 45% and 44% respectively).¹¹

Finding a cure and preventing MS are the top priorities among those affected by MS, clinicians and researchers. In the meantime, for those currently living with MS, other main priorities include preventing disease progression, maintaining function and maximizing quality

of life.^{12,13} About 15 years after diagnosis most people start to notice chronic loss of function and become dependent on mobility aids.^{14,15} Walking is an essential feature of independence and the most valuable functional activity challenged by MS progression.^{16,17} Although initial disease severity may predict the speed at which walking impairment may develop, once an individual's walking is impaired disease variables are less predictive of disease progression.¹⁸ Instead, individual factors such as attitude, PA levels, social support and financial resources influence quality of life and the development of additional functional limitations.^{19,20} Function is further impacted by co-morbidities and health behaviours.²¹ A recent study showed that PwMS who also had vascular disease were more likely to need a walking cane 6 years earlier than those PwMS without vascular disease.¹⁹

MS has a high socio-economic burden with the MS-related healthcare costs alone projected to reach \$2 billion annually by 2031 in Canada.²² Without a cure, disease-modifying therapies (DMTs) represent the first line of treatment, but are only modestly effective at slowing the rate of progression of neurological disability.²³ There are 13 DMTs for relapsing remitting MS and one for primary progressive MS currently approved by Health Canada.²⁴ DMTs reduce the proportion of PwMS who experience disability progression; however, disability is less commonly reversed or improved.²⁵⁻³⁰ Also, concerns remain regarding the short and long-term side effects, potential adverse events and cost of DMTs.³¹ Walking function (as measured by timed-walk tests) in DMT trials continued to decline,^{32,33} yet it improved in PA intervention trials.³⁴ It should be noted that PA trials tend to be shorter duration than drug trials.

With MS targeting young adults, causing early onset disability and no cure, there is a critical need to increase the use of non-pharmaceutical interventions to target symptom management, function and quality of life. Lifestyle factors in the routine management of MS have been historically neglected.^{35,36} The optimal management of MS, as with other chronic diseases, most likely requires a combination of pharmaceutical and lifestyle modification.³⁷

1.3 State of the literature: Importance of PA in the management of MS

There is substantial consensus in the literature that PA is a potent behavioural approach to MS management.^{38,39} Some researchers even consider it to be the most important non-pharmaceutical intervention for PwMS.⁴⁰ PA has been shown to mitigate symptom severity, and improve sense of wellbeing, coping, stress management and function.⁴¹ More

recently there is promising evidence that PA may have disease modifying impact as measured by decreased: relapse rate;⁴² CNS lesion load and volume on MRI,⁴³ and rate of progression.^{44,45} Further, PA is the best intervention available to address general health and functional ability (a primary goal for PwMS) and to minimize co-morbidities and their impact on overall health, function and well-being.⁴⁶ Although PA trials tend to be short in duration, functional improvement has been observed even in progressive MS.⁴⁷ Hence, PA is a low risk,⁴⁸ low cost⁴⁹ important intervention option for PwMS, irrespective of MS disease course, yet often not routinely utilized in MS care.⁵⁰⁻⁵²

Many different types of PA have been studied in MS. It is currently unknown what the optimal method and parameters are,⁵³ but there are unique benefits to be found in all forms of increasing PA with the least active individuals likely having the most to gain from increasing PA levels.⁵⁴ A recent meta-analysis has shown that walking was improved by several different types of exercise (yoga, tai chi, resistance training, aerobic), but suggests that a combination of resistance and aerobic training is best to improve walking function.³⁴ In an overly sedentary population facing barriers due to their MS, it is important to emphasize that there is benefit outside of structured exercise.⁵⁵ Changes in function can be seen with other methods of PA and changes in fitness, although highly beneficial, do not need to be observed to get functional benefits.⁵⁵ It is most likely that the 'best' form of PA is dependent on the benefit or outcome of focus (i.e. goal or reason for being active e.g. function vs. fitness), combined with tailoring the PA according to individual attributes (such as likes, supports, geographical location etc.). Considering function is a primary goal for individuals living with MS there is a lot to gain by increasing lifestyle PA and reducing sedentary behaviours. Recent guidelines exist for exercise prescription in MS, but these are only general guidelines, designed for individuals with mild to moderate disease severity and focused on exercise.⁵⁶ Although a start, little is known about the role of these guidelines in changing PA behaviour.⁵⁷

Historically, PwMS were advised against PA as it was thought to worsen symptoms and complicate fatigue and heat intolerance.⁵⁸ PA is now shown to be a safe and effective intervention.⁴⁸ Any increase in symptoms related to exercise is shown to be temporary.⁵⁹ However, this out-dated thinking on avoiding PA and fear of worsening symptoms may still be contributing to low PA levels.⁶⁰ This cycle of fear and reduced activity increases disability.⁶¹ HCP can play an important role in addressing this. A challenge identified by people with MS is finding the support and means to participate in regular PA.⁶² There is a need for interventions

to increase PA levels for PwMS. Individuals with MS have identified professional on-going support for increasing PA levels as both a research and clinical priority.^{63,64}

1.4 State of the literature: PA behaviour change for PwMS

Despite the numerous studies showing significant benefits to being physically active, activity levels in MS have changed little over the past 25 years.⁶⁵ Increasing PA behaviour is essential in order to benefit from the positive effects of being physically active and to mitigate the negative effects of a sedentary lifestyle.⁶⁶ Health status and the willingness to change behaviour are influenced by the interaction between a number of psychological, social and physical factors,⁶⁷ as outlined in the biopsychosocial model approach.⁶⁸ This approach recognizes that behaviour may be understood at several levels and designing interventions requires knowing which aspects of biological, psychological, and social domains are most important to understanding and promoting health.⁶⁹ Factors influencing health behaviour are numerous and can be represented in the international classification of functioning, disability and health (ICF) framework, based on the biopsychosocial model approach.⁷⁰ The ICF framework can be used to classify variables associated with PA behaviour into: 1) function (impairment, activity limitations and participation restrictions), 2) environmental and 3) personal domains. Those variables known in literature on PA in MS are summarized in Table 1.1

Table 1. 1 Variables and their Association with PA Behaviour in MS

Relation to PA ICF Domain	Consistent Positive Association	Consistent Inverse Association	Rarely Associated	Lack of Consistency in Findings
Function	Balance capacity ^{71,72} Muscle strength-lower limb ⁷³⁻⁷⁶	Overall disability level ^{71,72,74,79-81,97,106,111-117} Neurological impairment ^{85,87,113,118-126} Walking/mobility limitations ^{72,82,83,88,93,99,104,108,114,121,127-130} Activity limitations ^{75,77,78,91,122,124,125} Participation restrictions ^{86,122,125}	Type of MS ^{88,104,107,108} Pain ^{93,105,118,121}	Time since diagnosis ^{74,97,104,106-108,115,116} Fatigue ^{71,76,82,83,93,98,100,111,112,118,121,129,131,135,136} Thermo-sensitivity ^{108,131} Depression ^{93,100,112,118,121,135,136,137}
Personal	PA self-efficacy ⁷⁷⁻⁹⁹ General self-efficacy ^{82,100} Falls related self-efficacy ^{73,82,101} Self-identify ⁷⁹ Intention ⁸¹ PA goal setting ^{78,89,91,97,102,103} Action and coping planning ^{80,81} Education level ¹⁰⁴⁻¹⁰⁷ Employment status ^{74,104,107,108} Receiving health care services (e.g. PT) ⁷⁴	Perceived barriers ^{81,82,84}	Gender ^{73,74,79,104-8,112,115,116,131,132} Race ^{104,105,107,108} Income ^{104,108} Marital status ^{105,106,108} Knowledge of exercise effects on health ¹¹² Outcome expectations ^{78,89,91,103,106,133}	Age ^{74,105,108,115,116} Parental status ^{108,112} Perceived benefits ^{79,81,84,90,102,112,138} History of falls ^{73,139} Enjoyment of physical activity ^{86,112}
Environmental	Proximity to transit stop ¹⁰⁹ Social support ^{87,99,110}		Built environment (e.g. presence of sidewalks, street connectivity) ^{77,109}	Type of residency (urban vs. rural) ^{116,140}

Many of the variables associated with PA behaviour are modifiable and can be targeted by using BCS (also referred to as behaviour change techniques). A BCI is a coordinated set of strategies designed to target a specific behavioural pattern, such as PA.¹⁴¹ BCS/techniques are the active components of a BCI that bring about change.¹⁴² Examples of such components include goal setting and self-monitoring.¹⁴² A BCS addresses determinants of behaviour (such as those outlined in Table 1).¹⁴³ Behavior Change Theories describes the 'why' and informs selection of BCS. Several different theories have been developed to explain the complex process of behaviour change and to inform intervention development, with Social Cognitive Theory (SCT) being the most commonly used in MS PA research.¹⁴⁴ Overall, BCIs promotes utilizing a biopsychosocial approach to addressing PA levels.

BCIs are complex and multifactorial. Evidence shows that promoting exercise and education on benefits alone is not enough to change behaviour.^{145,146} It is recommended that BCS should be incorporated in PA promotion for PwMS.¹⁴⁶⁻¹⁴⁸ A successful approach to influencing PA behaviour should include assessing for determinants, applying BCS to target identified determinants, and monitoring for individual effectiveness.¹⁴⁹ A dilemma arising in trying to determine which BCS have the greatest influence in any given intervention, is the lack of consistent definition and terminology for these strategies.¹⁴² Despite this inconsistency in operational definitions for BCS, a recent systematic review on modifiable psychosocial constructs highlighted that PA related self-efficacy, self-regulation and perception of barriers should be targeted in PA behavioural interventions for PwMS.¹⁴⁶

Although BCIs have been shown to increase PA behavior, predictive studies have shown that determinants of PA behaviour predict about 20% of PA levels in PwMS.¹⁵⁰ In addition to the use of BCS, a recent study on BCIs recommended the added value of professional support in addressing PA behaviour among PwMS.¹⁵¹ PwMS appear to benefit from the intermittent support of a specialist with expertise in PA and MS to help maintain activity levels and function as the disease progresses.¹⁵² PwMS want this support to address PA behaviour to come from HCP.^{63,64} A HCP is defined as an individual who provides preventive, curative, promotional or rehabilitative health care services in a systematic way to people, families or communities including health experts.⁷⁰ Further, MS is a highly variable disease with periods of symptom and functional fluctuations; hence, access to follow-up with an expert knowledgeable about MS and PA is a recommended, albeit not routine, part of care.¹⁵³ Ensuring that HCP have the tools

to address PA behaviour, including how to facilitate behaviour change, as part of this support is critical.

The modification of health behaviours, such as PA, is well established in the management of other chronic diseases (e.g. diabetes and cardiovascular disease).¹⁵⁴⁻¹⁵⁶ Although most PwMS want and actively seek lifestyle advice, there are currently few guidelines and no mainstream management strategies incorporating the support needed to make meaningful changes to lifestyle behaviour.^{157,158} While there is evidence for implementing PA in the management of MS as well as evidence to incorporate BCS and HCP support to optimize PA efforts, there is no research on the effectiveness of HCP use of BCS for PA promotion among PwMS. This lack of research may reflect a gap in knowledge translation. This thesis provides an important step toward investigating gaps in knowledge translation and clinical application of PA behavioural interventions for PwMS.

1.5 Methodology: Interpretive Description, a qualitative applied science approach to capture end-users perspectives (both HCP and PwMS)

Qualitative research includes a variety of interpretative techniques with the common aims to describe the meaning and significance of certain phenomena and to attempt to understand experiences according to those who live them.^{159,160} Qualitative research emphasizes the individual and local knowledge necessary to effect meaningful change and can help with moving quantitative knowledge towards application.^{161,162} Including qualitative methodology in healthcare research is useful to identify what is most important to both clients and clinicians. Qualitative approaches allow a depth of investigation needed to consider the intricacies of client-clinician interaction and to identify barriers to change, as well as the reasons behind certain behaviours.

Exploring the perspectives of end-users of the research, including PwMS and HCP, will enhance the relevance of research to actual health behaviours and decisions these end-users face. An increased relevance is thought to improve uptake of the evidence increasing the value of the research by improving the likelihood that PwMS will achieve meaningful changes in PA behaviour needed to obtain benefits.¹⁶³ Health care, behaviour and neurological disease are all complex and multifaceted. A qualitative approach allows researchers to dive deeper into understanding these complex situations. A qualitative methodology is one desirable approach

to reveal knowledge useful to inform future interventions to target the localized needs, minimize knowledge to practice gaps and maximize meaningful change.

As such, the primary methodology in this thesis is Interpretive Description. (ID).¹⁶⁴ ID is a qualitative research approach designed for applied disciplines such as health professions. It acknowledges that HCP work on informed action, and while many components of HCP' work are based on conventional science, much has to do with the human experiential and behavioural world of applied practice.¹⁶⁵ This requires a distinct form of inquiry. ID was created to meet the need for research methods that could explore human experience and behaviour with the goal of producing useable knowledge relevant to an applied health field.¹⁶⁵ ID is grounded in a non-dualistic philosophical tradition and emphasizes that 'reality' is not an objective entity, but instead is more usefully understood as being socially constructed through lived experience.¹⁶⁵

Focus groups are a type of data collection tool used in qualitative research. Focus groups were used in this thesis to encourage rich interaction between participants.¹⁶⁶ Interaction can facilitate sharing ideas and spark discussions that further illuminate a topic. This level of discussion allows explanation of participants' lived-reality revealing potential problems to implementing certain interventions and providing a platform to share details.¹⁶⁷ Often such process ignites a problem solving approach and the process of research becomes an intervention in itself. Researchers learn more than what the research sets out to discover, revealing the root or sometimes the vastness of a phenomena.

1.6 Overall context for research manuscripts

This thesis is a timely and essential step to begin to close the knowledge to practice gap and enhance PA behaviours given the numerous benefits, yet low PA levels for PwMS. Addressing PA behaviour and finding ways to translate evidence into clinical practice have been identified as top research priorities in MS PA research.¹⁶⁸ This PhD research is a starting point to help improve HCP and PwMS knowledge, use and ultimately change in PA behaviour in the management of MS. Key steps towards improving the use of PA behaviour change in the management of MS include exploring the current perspectives and practice from the standpoint of PwMS as well as HCP working with PwMS in SK with regards to PA behaviour change, as done in Chapter 2 and 3 of this thesis.

Examining current practice and perspectives to identify strengths and challenges from the viewpoints of the lived-experience of HCP (Chapter 2) and PwMS (Chapter 3) is important to identify targets for improving care. The rationale for exploring perspectives of both PwMS, as well as HCP working with PwMS was to maximize the alignment of future research interventions and intervention material with the context in which they will be implemented. The following 3 chapters include manuscripts representing studies undertaken to further knowledge on this matter: What are HCP currently doing with respect to addressing PA behaviour in the management of MS (Chapter 2); What do PwMS perceive their HCP are doing regarding PA and what are their priorities and solutions (Chapter 3), and, building on key findings of Chapter 2 and 3, what can be found in the literature with regards to preparing HCP to use PA BCS (Chapter 4).

Despite being a research priority, to the best of my knowledge there has been no published PA behavioural intervention studies for PwMS carried out in Saskatchewan, and only one in Canada.⁹⁰ There have been no studies looking at HCP' use of BCS in the routine management of MS (Chapter 2), and only 1 study looking at HCP role in PA promotion.¹⁶⁹ There have been two qualitative studies looking at what PwMS want from HCP targeting PA behaviour,^{63,64} but no studies looking at proposed solutions from the perspectives of PwMS (Chapter 3). There is a paucity of literature engaging PwMS themselves to inform research that can and will directly impact them.¹⁷⁰ Informed by results of the qualitative studies discussed in Chapters 2 and 3 emphasizing the need to increase HCP knowledge, confidence and use of BCS, a systematic review (Chapter 4) was conducted. This review uniquely focused on the reporting of training HCP as interventionists to deliver BCS. Together these three novel studies provide new knowledge crucial to informing the nature, priorities and feasibility of future research and interventions targeting PA behaviour change in the routine management of MS in SK.

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CHAPTER 2: A Qualitative Account of Health Care Professionals' Current Practice and Perspectives on Addressing Physical Activity Behaviour in the Management of Multiple Sclerosis

THIS MANUSCRIPT IS CURRENTLY UNDER PEER-REVIEW

2.1 Abstract

Background: PA is considered one of the most important non-pharmaceutical interventions for PwMS. Despite this, less than 20% of PwMS are engaging in sufficient amounts of PA to accrue benefits. PA promotion is most effective when combined with additional BCS, but this is not routinely done in clinical practice. The purpose of this study is to increase our understanding of current practice and perspectives of HCP with respect to their use of interventions to address PA behaviour in the management of MS. Investigating HCP' perspectives on implementing PA behaviour change with PwMS may provide insight into this knowledge to practice gap.

Methods: Semi-structured focus groups were conducted with physical therapists (PTs), occupational therapists (OTs), nurses and physicians (n=31) working with PwMS in SK. Based on ID, data were coded individually by three researchers, who then collaboratively developed themes. Inductive thematic analysis, triangulation and member checking were used.

Results: Five themes were established: 1) Prescribing, promoting and impacting wellness with PA; 2) Coordinating communication and continuity in practice; 3) Time, access and relevant care; 4) Enhancing programming and community-based resources and 5) Reconciling perspective, theory and practice.

Conclusion: HCP value PA and desire more support with application of BCS to deliver PA behavioural interventions, but due to acute and reactive nature of health care systems, feel this cannot be prioritized in practice. Both individual- and systems-level changes are needed to support consistent and effective use of PA behavioural interventions in MS.

Key words: multiple sclerosis; behaviour change; physical activity; multidisciplinary care; interpretative description;

2.2 Introduction

MS is a chronic progressive neurodegenerative disease. There is growing evidence for the benefits,¹ safety² and importance of being physically active in the management of this disease.³ These benefits extend beyond enhancing general health and wellbeing, to also include potential disease-modifying effects, supported by MRI outcomes and research in MS animal models.⁴ Physical activity is considered the most important non-pharmaceutical intervention in the management of MS.⁵ Increasing one's PA levels as part of everyday life, or through engagement in structured exercise, should be considered an essential component of a comprehensive management plan for PwMS.⁶ Current data indicates that PwMS are far less active than age-matched healthy populations.⁷ HCP working with individuals with MS play an important role in the management of this chronic progressive and currently incurable disease. Symptom management and lifestyle interventions including PA have been identified by PwMS as a priority and should be routine, prioritized components of health care interventions.⁸ Studies focused on PA have shown that PwMS: 1) have received mixed-messages about whether or not to and how to be active from HCP;⁹ 2) do not feel HCP regularly promote engagement in PA;¹⁰ and 3) want advice from their HCP to optimize their PA behaviour.¹¹ It has been observed that PwMS more commonly seek advice on lifestyle approaches than pharmaceuticals for disease management.¹²

The inconsistent use of PA behavioural interventions by HCP in routine care is an important contributor to the low levels of PA observed among PwMS.¹⁰ Simply educating clients about the importance of being physically active is not sufficient to initiate and maintain increased engagement in PA on a regular basis in the face of a progressive neurodegenerative disease.¹³ A current theme in the literature is that initiatives to increase engagement in PA with neurological populations should also include BCS.¹⁴ BCS are the active components of a BCI.¹⁵ A BCI is a coordinated set of strategies designed to target a specific behavioural pattern, such as PA.¹⁵ BCS are ways to ensure optimal effectiveness of healthy lifestyle promotion and include components such as assessing self-efficacy, barrier identification and problem solving, which combined can enhance intervention implementation.¹⁴

It is still not known how to best translate PA research for PwMS into clinical practice¹⁶ and exploring the viewpoint(s) of clinicians is integral in determining how this might occur. This study aimed to investigate the current practices and perspectives of HCP in their application of PA behaviour interventions when working with individuals with MS. Knowledge

from the lived experience of HCP will serve to inform future interventions at diverse levels within our health care system, that will be meaningful to all end-users – including HCP and PwMS. This knowledge may also impact how health care services are delivered. Future interventions based on the current needs and perspectives of HCP will enhance applicability, minimize knowledge-practice gaps and maximize clinical implementation that will all positively impact the lives of PwMS.¹⁷

2.3 Methods

Design:

ID, an applied qualitative research approach, was the methodology used in this study. ID was inspired by more traditional qualitative approaches and created to meet the demands of clinical inquiry in health science.¹⁸ A key feature of ID is the integration of knowledge development in relation to clinical experiences, such that new insights informing clinical practice can be obtained.¹⁸ The development of this study has been informed by previous clinical work and research. All authors are Western trained physiotherapists (although trained and practicing in different locations in Canada, Australia, and New Zealand), and as such, bring a biopsychosocial lens to this research. This study was approved on ethical grounds by the Research Ethics Boards of the University of Saskatchewan, Regina Qu'Appelle Health Region and Prince Albert Parkland Health Region.

Sampling and recruitment:

Participants were HCP who were recruited using purposive convenience sampling. The main health regions across the province were involved to recruit from a variety of HCP across clinical settings (e.g. acute care, inpatient rehabilitation, outpatient rehabilitation, and community/homecare). For study inclusion participants had to be: 1) a HCP, and 2) have worked with PwMS in SK for a minimum of one year. For participant demographics see Table 2.1.

Table 2.1: Participant Demographics HCP

Type of HCP:	Count (n=31)
Neurologist	4
Nurse	3
OT	7
Physiatrist	4
PT	13
Clinical setting:	
Acute care	7
In-patient rehab	5
Out-patient rehab	4
Community/home-care	7
Across contexts	8
	Years
Years working clinically with PwMS	mean: 21 (+/- 9) median: 18 mode: 25

Data Collection and Analysis:

Data collection and analysis were inductive and iterative. Consistent with an interpretative approach, researchers kept field notes and journaled on impressions following each meeting. Minor modifications to the semi-structured interview guide were made accordingly throughout the data collection process.

Two of the researchers (SJD and KEM) conducted semi-structured focus groups at each participating location. One researcher (SJD) was present at all interviews, and due to the need to travel, the other researcher (KEM) connected via teleconferencing to capture field notes and impressions. Focus group meetings lasted 43–68 minutes with group size ranging from three to eight participants. A semi-structured interview guide was used (Table 2.2). After each focus group, participants were contacted a week later and invited to share any further reflective responses. Participants were also invited to review the original transcript from their focus group and provide any additional insight.

Table 2.2 Sample Question Guide from Semi-Structured Focus Groups HCP

1. *Do you recommend increased PA or exercise for PwMS?*
2. *Is increasing PA or exercise for PwMS a priority for you?*
3. *Whose job do you think it is to promote PA for PwMS?*
4. *What strategies do you have to help promote increased PA for PwMS?*
5. *What do you feel is the biggest limitation to prescribing and successfully implementing increased PA or exercise for PwMS?*
6. *What do you think could help increase PA and/or exercise for your patients? Are there things that you'd like to change regarding your use of PA or exercise in the management of MS?*
7. *What do you think is an ideal process for increasing PA for PwMS?*
8. *Do you know about BCS? Do you currently use BCS for health promotion in your practice?*
9. *What do you feel are the biggest limitations to using BCS?*

For accuracy, and to aid in analysis, an active transcription process was used where one author (SJD) reviewed the transcripts several times relative to corresponding audio recordings to thoroughly capture nuances of words, phrases and delivery to hear more deeply what the language contained.¹⁷ After member checking, transcripts were independently analysed by three researchers (SJD, SO, KEM) using whole data immersion. Preliminary codes were then discussed as a group. Using the preliminary code, three researchers (SJD, SO, KEM) independently reviewed the transcripts again prior to further group discussion designed to share and resolve any discrepancies. Transcripts were then imported into NVivo 11 (QSR International Pty Ltd, Melbourne, Australia) for formal coding, and analysis. Transcripts were reread numerous times to review interpretations, and similarly coded segments were compared to ensure consistently applied coding.¹⁹ Through comparative and iterative analyses, codes were added and adjusted as needed. The researchers (SJD, SO and KEM) discussed and labeled five resulting themes informed by their clinical research perspectives.

Triangulation was used both in data generation (member checking of focus group transcripts and reflective accounts) and in the data analysis process (three researchers independently coding). Notes about research and decision-making processes were kept to ensure a thorough analytical process²⁰ where the quality and nature of findings were congruent with the research process.

2.4 Results

Five overlapping themes were identified and labeled (depicted in figure 2.1). These themes depict the experiential reality of HCP working with PwMS in SK with regards to interventions addressing PA behaviour: 1) Prescribing, promoting and impacting wellness with PA; 2) Coordinating communication and continuity in practice; 3) Time, access and relevant care; 4) Enhancing programming and community-based resources, and 5) Reconciling perspective, theory and practice.

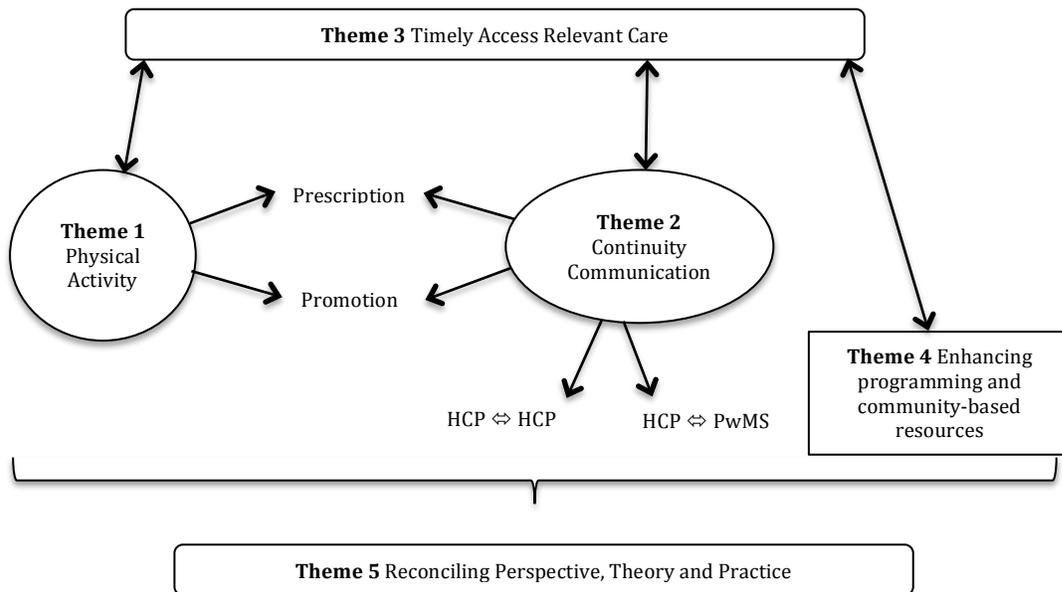


Figure 2.1. HCP Results: Five Overlapping Themes

2.4.1 Theme 1: Prescribing, promoting and impacting wellness with PA

HCP noted that there was a difference between promotion and the prescription of PA. They acknowledge that saying one should be exercising (promotion) and implementing a program to actually meet this advice (prescription) are two very different things. Certain HCP (PTs and exercise specialists) were suggested by most participants as being the ideal professionals to fill the ‘prescriber’ role. PTs affirmed this statement but also admitted that there are numerous barriers to being able to successfully implement a PA behaviour change intervention for PwMS (elaborated in more detail in later themes). Participants feel that implementation success is enhanced when all members of the health care team promoted PA. The consensus was that everyone needs to be promoters of the message but in particular

neurologists and family doctors, and that promoters need to take a more active role in referring onwards to prescribers. Neurologists and family doctors were seen as influential promoters and the HCP that PwMS most regularly see.

“PT3: We all have to be on the same team. And it’s everyone on the team’s job to promote physical activity if we want it to work.

OT1: Yeah, I was going to say. The whole team, really.

PT4: Yeah it can’t be just us, because if everyone’s not being consistent and saying the same things, it’ll be too hard to do it all on our own.

OT1: Well if you get one person on that team, particularly a physician, not promoting that, they’re the ones that tend to be listened to. “

Promoters should be more aware of existing resources or community experts (if any) in MS PA prescription and use them as part of their promotion. Prescription should be individualized, expert informed, monitored and supported over time. As one physiatrist noted, “physicians need to recommend it. But I don’t think that physicians need to prescribe. They don’t have the expertise, or the time, or the resources even. We need prescribers.” Monitoring and providing ongoing support were recognized as particularly challenging by the different HCP: “I don’t know how much my patients are actually doing it. I don’t monitor it – I don’t have time. (PT12)”

Prescribers need to increase their use of behaviour change theory and strategies to facilitate an individualized process that is meaningful to individuals with MS. In one neurologist’s experience “it’s really easy to get someone excited about it, but it’s very different when they wake up in the morning and they’re tired as hell and they actually need to motivate themselves. I don’t know how to.” Overall, the priority of PA as a component of wellness in the management of MS is there in theory, and appears as though the role of PA in the management of MS is valued, but addressing PA behaviour is not a consistent part of routine practice. As summed up by PT9 “we need everyone to promote, but someone specific to prescribe, monitor and problem solve.” This quote highlights the importance of including BCS with PA interventions.

2.4.2 Theme 2: Coordinating communication and continuity in practice

All participants valued the role of PA in the management of MS, however, several noted that there were times when inconsistent messaging was being delivered from diverse HCP

team members to PwMS. Mixed-messaging regarding PA creates confusion and barriers to implementation success. “The family doctor had said, ‘stop exercising.’ The way they told it to me. They were told to stop exercising completely, and ahhh that can’t be right or that’s incredibly outdated thinking. But it still happens.” (Physiatrist3) The need for consistent messaging, training and updating among practicing clinicians as well as improved communication between HCP and PwMS is viewed as essential. “We need to dismiss fears around exercising and the fact that it’s not causing harm. We need expert informed and more consistent access, otherwise it won’t be sustainable.” (Physiatrist1)

There is also a strong need to improve communication between HCP across health care contexts. “There seems to be a lack of communication between neurologists and the physiatrist. I don’t understand the history behind that.” (PT4) There is concern as to how to make sure messages are more consistent, knowledge of options are more consistent and client experience is more consistent. There is the absence of a consistent pathway for PwMS. This lack of continuity means that PwMS are often left to be their own self-advocates (and/or look to other less-trained individuals who may not fully understand the intricacies of MS to safely support or prescribe exercise to PwMS). A number of participants were unaware of existing resources such as a MS nurse, new diagnosis packages through the MS Society, existing guidelines for PA in mild to moderate MS, or even the most recent evidence for PA effectiveness in the management of MS.

“Physiatrist1: You have to know what’s available.

Neurologist1: I definitely don’t.

Physiatrist2: I think historically there have been better community-connections. I don’t always feel like I’m up to speed. It would be great if we could know about what’s going on in the community or had a way of staying on top of it.”

When considering communication, a way to stay up to date with the scientific evidence and best practice guidelines should also to be considered. Across all disciplines there was a lack of awareness of what resources do exist paired with the belief that there was also a lack of resources (elaborated on in theme 4).

2.4.3 Theme 3: Time, access and relevant care

The view that current practice lacks emphasis on promoting, prescribing and monitoring PA behaviour was consistent across disciplines and health care contexts, and was

attributed to a lack of time, access and resources. As one nurse said “there are just a lack of resources in the community and health region, and barriers. Real barriers and we need someone to help them [PwMS] problem solve.” Regarding time, HCP expressed concerns with the infrequency of visits to MS speciality clinic (e.g. only annually or bi-annually), long waitlists (for rehabilitation services), lack of follow-up, and the short length of time they are able to spend with PwMS. Concerning which HCP could best prescribe exercise for PwMS, Physiatrist1 felt “PT is ideal, but ... our system is stretched from the physio perspective, and there are other things that physios need to do.” This suggests that there are barriers at the health system level.

Many HCPs expressed that their interactions with PwMS were based around triaging problems and treating in a reactive nature. For example, prescribing a new wheelchair or assistive device, or addressing a recent onset of foot drop:

PT11 “Our system is too reactive. Someone has foot drop and now we will put on a brace. I’m not saying that’s not important, it absolutely is with the progressive nature of MS. They usually have a wait-list for that appointment too and as their assistive needs change they become less active while they wait. But then, I think there is such a need to have a proactive element. Time to get them more active and more rehab before they start to progress.” This quote is one of many representing the HCP’ concerns with timely access to relevant care.

Regarding access, participants reported a lack of specialists for MS and lack of opportunity to have advanced practice in MS care. “It would be really nice to be able to refer to a specific MS expert, resource or exercise program.” (Nurse1) At the time of the study, little was known about the provincial geographical distribution of PwMS, but participants reported limitations in MS specialty care even in urban settings. Rural services are needed. A limited number of MS Nurses and no rehabilitation services dedicated for PwMS throughout the province were also reported resource concerns.

HCP may not see PA as value-added given the energy demands already in place for PwMS. Participants repeatedly reported a tension between the fact that MS is a progressive neurodegenerative disease with energy issues so why would being physically active be a priority for PwMS. PT7 “I think one of the most limiting barriers is that they just don’t have the energy to do everything they need to do in a day. So then you ask them to exercise as well, well getting dressed is already exhausting for that patient. Then there’s the catch 22 that exercise can decrease fatigue but you’re too fatigued to exercise”. Several of the barriers to PA that HCP reported PwMS having (e.g. fatigue, spasticity, balance and mobility issues) are actually shown

to benefit from exercise. More information is needed for HCP about benefits and how to influence PA behaviour. To augment this, more research is needed to inform optimal PA parameters and implementation.

PT2 “If I have time I’ll promote exercise, but I don’t monitor adherence because I don’t have time or there’s no time for follow up.” Long waitlists, access and resource issues contribute to the reactive nature of the health care system. A change in services should consider the needs of PwMS so that the system is relevant to both PwMS as well as their HCP.

2.4.4 Theme 4: Enhancing programming and community-based resources

HCP pointed out that compared to the other neurological or chronic disease populations they work with, MS is underserved. PT1 “Well what we’re forced to do is try and take our MS population and plug it into community-based programs that don’t exist. We have such limited services right now.”

Along the lines of the lack of resources and access described above in theme 3, the underserved component was highlighted by multiple HCPs expressing concern that they have nothing to refer their clients to. Many participants were unaware of what, if any, community resources exist. As stated by one PT6 “...there’s the MS clinic... above and beyond that, I don’t think we know what other resources there are. I think part of the problem too is because we only see that immediate or very short period of time in acute care, that we don’t do the follow-up. There isn’t the same incentive or the same expectation that we should be as familiar of what’s out there.” PT4: “after their acute stay, they fall off the radar and there’s very poor follow-up generally.”

HCP desire a provincial MS specific pathway that considers community resources and/or more accessible outpatient services for PwMS. PT1 “Why can’t we have a seamless pathway to move through from diagnosis to support in the community, which would require more support in the community?” A model that builds and/or borrows from other chronic diseases, such as the ‘live well’ program (for arthritis, diabetes, cardiac, stroke), was suggested. Nurse3: “Why can’t we just have an MS-specific program there with flexible hours that people can attend with expert input? We have nothing compared to cardiac rehab.” Physiatrist4: “We should have and need more resources like other chronic diseases”

2.4.5 Theme 5: Reconciling perspective, theory and practice

There was a clear message that HCP value PA, yet it is not being prioritized in practice, for seemingly diverse reasons. Physiatrist3: “ I think we can do better at educating and providing hope. I don’t think people think about exercise as being healthy for the brain. We can do better at counseling to find what they like and monitoring it. Just putting more effort in, rather than just saying exercise”

Similarly, participants knew what BCS were, but were not able to give tangible examples of their use in clinical practice. Education and goal setting were the examples given by HCP of types of behaviour change strategies given. PT3 “ I guess it would help if I could implement behaviour change strategies with their physical activity, but what does that mean- what would it look like?” There was desire to learn more about how to implement BCS for healthy lifestyle behaviours, including PA. Scepticism was noted about the ability to change practice, even with increased knowledge of BCS, in the current system. Perhaps there should be a priority to change the current health service delivery for PwMS based on comments suggesting that SK, having one of the highest rates of MS worldwide, should have state of the art MS care.

Potential solutions were offered to improve the use of BCS and successful implementation of PA for PwMS. These included: an MS specific clinical pathway; a website or some sort of updated system to communicate the availability of resources and how to access them; more MS nurses and MS specific rehabilitation specialists; a method to support better integration of existing evidence and resources such as the local branch of the MS Society, and creating more resources both in terms of PA community classes but also educational and referral material for PA promoters.

Physiatrist2: “Ideal would have to have a way that we could influence them to carry on activity. More follow-up, more expertise, more options, coaching. There’s no one answer” PT2: “We need a re-shift in focus on behalf of the health region, ministry, everybody – they could reduce the burden so much by focusing on prevention more in acute care and early diagnosis”

2.5 Discussion

The main purpose of our study was to document the current perspectives and practice of HCP working with PwMS with regards to changing PA behaviour. The findings of this study suggest that HCP are aware of the importance of addressing PA behaviour, but are not able to prioritize and successfully implement PA changes with PwMS in the current health care system.

Consistent with previous literature, it is not the approach of our health care system to focus on proactive lifestyle and wellness interventions.²¹ This is perhaps a component driving the complexity of why PA prescription is not prioritized, even among HCPs who believe in it and some who are well versed in it. It is evident that our health care system, and the ways in which we deliver care, are not optimally designed to successfully and safely prescribe PA to optimized health and function, particularly for PwMS. Successful implementation includes using BCS to facilitate the process of prescription,^{6, 10, 11} and, according to proposed solutions from this study, needs consistent messaging and promotion across disciplines with opportunities for follow up to monitor adherence and allow on-going expert support. With the progressive and variable nature of MS, this on-going support enables access to relevant care needed to adapt programs in an individualized client-oriented manner. Operating in an acute-care paradigm with competing priorities and limitations in access and treatment time, HCP interventions are often focused on reactive impairment specific issues (e.g. prescribing walking aids and assistive devices, dealing with pressure sores) as opposed to prevention.

The perspective that the health care system is reactive in nature is not unique to MS care,²² but appears to be a driving factor in HCP delivery of MS care. Given the way health care is delivered to individuals living with a chronic condition, and within a rural health context, is it that there is only so much one can focus on in one interaction/health appointment? With advancements in disease and symptom management options, the critical question is how do we streamline the delivery of MS care within health facilities and within communities, to meet the broad and diverse needs of PwMS. A general shift of focus to prevention and better lifestyle management for this chronic disease is needed as there appears to be great value in this type of care for PwMS.²³ Who owns this responsibility is an important question. Individual level change should involve HCP taking ownership rather than placing all the blame on the health system.²² Extrinsic barriers do exist that need to be addressed with health care system change, but still HCP need to take more ownership in what they can do. Perhaps there is not enough self-reflection over what the individual HCPs have control over and their role in the situation.²⁴ Individual and systems level changes are needed to enhance comprehensive management of MS including the prescription of tailored PA for PwMS.

Consistently voiced was the lack of resources to successfully address PA behaviour. HCP feel their time is prioritized to 'put out fires' yet most agree that increasing PA levels for PwMS would target and enhance many treatment priorities (e.g. fatigue, balance, function). Overall

there is a reported lack of the time, follow up and/or resources to prescribe/monitor physical activity in a way that is meaningful to PwMS. Financial barriers were apparent with repeated reference to long wait lists, lack of follow up, understaffing and a small number of HCP with expertise in MS care – all of which are costly resources. Budget cuts are now a reality of the health care system however, our study's findings also mentioned a lack of several low-cost resources as a barrier to promoting PA management options. Lack of localized informational material on PA resources for PwMS, client specific material for PA, a list of who and/or what HCP can refer to, to meet individualized PA goals were among those mentioned. Most HCP expressed the desire to learn more and have more resources on BCS – perhaps unique for neurodegenerative diseases. Most reported that education is the main strategy they use when they promote increasing PA. Promotion and education can be enhanced through resources available to HCP such as guidelines, brochures for HCPS on benefits, warnings and precautions, resources on what is available in the community to refer to for prescription, as well as increasing HCP own knowledge and use of BCS.

Although systemic and resource barriers exist, there are other chronic disease models (such as cardiovascular disease or arthritis) that can provide potential models to inform community programs for PwMS.²⁵ Community based alternatives could be used to decrease the cost of care,²⁶ but there also needs to be community resources that exist and can be customized to the local needs of PwMS. From the HCP perspective in this study, an ideal community resource should be structured, expertise informed, have a social and support element, be ongoing, accessible, and involve elements of behaviour change to encourage out of session/program maintenance. To address individual needs, besides a community program, interventions to enhance PA behaviour require options in delivery methods, such as in home programs for those with access or geographical barriers delivered through innovative methods such as web-based programs or existing Telehealth networks.²⁷

Improving communication and consistency of messaging across HCP and health care contexts is a low-cost, and potentially cost-saving, solution that should be a priority to enhance the overall management of MS, including PA interventions.³ HCP expressed that it is everyone's job to promote exercise, and the PTs and/or exercise specialists role to prescribe. The effectiveness of such a model would require all HCP to become active promoters, and to know of and refer to prescribers, further emphasizing the importance of communication and consistent messaging. Successful implementation requires more resources, time, expertise and

the establishments of a structured program provided long term in the community. There also needs to be a way for HCP to keep up to date with this information. There is currently no system in place to train in-coming HCP, a reported lack of opportunity to have advanced practice in MS, and also no provincially shared pathway for MS clinical care. This expands beyond the scope of PA, but the reality is that MS care overall needs to be improved in order to enhance management and lifestyle interventions including PA. An environmental scan to inform the development, implementation and evaluation of a provincial clinical pathway could improve MS care. In other neurodegenerative populations such as amyotrophic lateral sclerosis, lifespan is increased by the use of dedicated clinic care pathway(s).²⁸ A pathway that considers the unique and localized needs of the people it is serving is likely to be an ideal framework. Geographical considerations such as rural living, winter conditions, as well as low population density and how these factors can impact continuity of care need to be addressed. A provincial pathway may help to alleviate these challenges and improve communication.

All of these themes are inter-related. Key suggestions to enhance MS care and address PA behaviour in the management of MS based on the findings in this study are summarized in Table 2.3. There is a need for more resources, but what good are those resources if no method of communicating their availability and if access to HCP is limited? HCP need to be active promoters of PA, but there needs to be a system in place to increase HCP awareness of resources in addition to ensuring resources are meeting the needs of PwMS prioritizing a client-centered approach to chronic disease management.

Table 2.3 Key Suggestions, based on HCP findings, to enhance MS care and address PA behaviour in the management of MS

<p><i>Improve communication across the health care continuum</i></p> <p><i>Develop, implement and evaluate a Provincial MS Clinical Care Pathway</i></p> <p><i>Increase community resources to meet the PA needs of PwMS; build off of other chronic disease models</i></p> <p><i>Increase HCP knowledge and confidence in using BCS for PA interventions</i></p> <p><i>Increase options for HCP to gain expertise and advanced practice in MS</i></p> <p><i>Development of low cost localized resources to help HCP with PA promotion</i></p> <p><i>Explore novel PA delivery options to allow on-going support as PwMS needs change</i></p>

Limitations and future research

This study included a variety of HCP from across the province, but did not have general medical practitioners (GPs). Future research investigating communication and pathways among HCP should involve GPs, as they are seen as influential in PA promotion (theme 1). HCP prioritize PA in theory, but there is a gap in perspective and practice. PA and behaviour change should be one and the same but theory and practice are often different. There is a need for future studies to explore these concepts in more depth. Future research should also consider interventions targeting HCP but not without consideration for implementation such as participatory health research process or an integrated knowledge translation (iKT) method to enhance communication. Multilevel conceptual frameworks and mixed-methods approaches are needed to attempt to capture the complexity and the heterogeneity of the mechanisms, processes and outcomes of change.²² As solutions are identified, they can also be incorporated into care pathways and health system priorities – addressing both individual and systems level change.

This qualitative account of HCP' current perspectives and practice has shown that HCP value PA and want more information on BCS and their use in order to be more effective in changing PA behaviour for PwMS. Unfortunately due to the acute and reactive nature of the health care system HCP feel they cannot prioritize this in practice. Both systems and individual level change are needed in order to support consistent and effective use of PA behaviour interventions in the on-going management of MS.

Clinical Practice Points

Addressing PA behaviour in a manner that is meaningful, relevant and appropriate for PwMS is complex. Change needs to occur at both the individual HCP and the health care system level. Increasing HCP' knowledge, confidence and skills in using BCS for PA interventions and increasing opportunities to gain expertise and advanced practice in MS could target individual level change. Novel delivery options to allow on-going support as the needs of PwMS change should be explored. Enhanced community design may be one way to mitigate access issues and could be informed by other chronic disease models as a component of systems level change. New resources should not be created without considering communication across health care contexts and between HCP.

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CHAPTER 3: Proposed Solutions for Improving Physical Activity Behaviour from the Perspective of Persons Living with Multiple Sclerosis: A qualitative account

THIS MANUSCRIPT IS CURRENTLY UNDER PEER-REVIEW

3.1 Abstract

Purpose: PA has substantial benefits in the management of MS. However, PwMS are far less active than needed to accrue benefits. This study aimed to investigate the priorities and proposed solutions for influencing PA behavior from the perspectives of PwMS.

Method: ID and semi-structured focus groups were the qualitative methodology and data collection methods used in this study. Participants (n= 24) were individuals living with MS. Inductive thematic analysis, triangulation and member checking were applied in data analysis. Data were coded individually by three researchers, who then collaboratively developed themes. Themes were checked by an additional researcher who analyzed transcripts through the lens of the themes to look for confirming, negating or additional concepts.

Results: Four main themes highlighting priorities and proposed solutions were established: 1) Consistent messaging regarding PA; 2) Support throughout disease progression; 3) Community programs with expert input that clinicians know about and to which they refer, and 4) Training for and access to specialists.

Conclusion: Understanding the experiences of PwMS is essential if HCP are to provide appropriate support to influence PA behaviour. Incorporating the perspectives and proposed solutions based on the lived experience of individuals with MS provides essential knowledge to inform the development of meaningful changes in health care. Future interventions based on these findings will enhance relevancy and maximize implementation.

Key words: physical activity; multiple sclerosis; patient-oriented research, behaviour change; interpretive description;

3.2 Introduction

MS is a chronic neurodegenerative auto-immune disease primarily affecting the CNS. It is the most common neurological pathology affecting young adults, with a typical diagnosis occurring between the ages of 20-40 years.¹ Unfortunately, despite advances in medical management there is currently no cure. MS is a highly variable disease, but being progressive in nature most living with MS experience a gradual accumulation of disability.² With a host of invisible symptoms such as fatigue, pain and cognitive issues, even those in a remission have daily fluctuations.³ Many PwMS have a typical lifespan, but with young onset, no cure and disease fluctuations, most people need continued support and access to health care.⁴ The chronic and variable nature of MS makes it difficult to predict which supports may be required and when. There is a need to improve provision of meaningful management options for PwMS.

PA is proposed to be the most important non-pharmaceutical intervention in the management of MS, yet most individuals with MS are far less active than needed for health benefits.⁵ There is growing evidence on the importance of PA in the management of MS, but a consistently small percentage of PwMS participate in PA.⁶ This gap between evidence and practice highlights the importance of research on methods to improve PA behaviour. To improve our ability to answer questions about optimal parameters and the disease modifying capacity of PA we need to increase and maintain PA levels. We need to identify feasible interventions that increase PA levels, while meeting the diverse needs of PwMS. An essential step in achieving this goal is to explore the lived experience of PwMS to inform meaningful and relevant solutions. As PwMS have been underrepresented in the literature on healthcare services,⁷ there is a need for knowledge gained from the lived-experience of individuals with MS with regards to PA behaviour.

The aim of this study was to explore the perspectives of PwMS with regards to their priorities and proposed solutions for influencing PA behaviour in the management of MS. Investigating proposed solutions from the participants' perspectives is a novel approach to lessening the evidence to practice gap. Elements of human-experience can help to better understand health and client needs that can be used to optimize the care health professionals provide.⁸ Further serving to generate new insights on what is clinically relevant, meaningful and applicable to clients. Moving beyond only identifying barriers and facilitators to focusing on solutions values the lived-experience and knowledge derived from this process, putting a positive action oriented lens on the issue.⁹

3.3 Methods

This study used ID, an applied solution driven qualitative research approach suited to the desire for findings to influence clinical application.¹⁰ The Research Ethics Boards of the University of Saskatchewan approved this study on ethical grounds.

The development of this study has been informed by previous clinical work as well as clinical research. All authors are physiotherapists (although trained and practicing in different locations in Canada, Australia, and New Zealand). In terms of disciplinary scope this lends integrity to the research process as clinical experience facilitates high-quality interpretation and description involved in an ID approach.¹⁰

Sampling and Recruitment

This study took place in SK, Canada. Recruitment was through the local branch of the MS Society and through the SK MS Clinic and corresponding research database. For study inclusion participants had to have a physician-verified diagnosis of MS. Purposive sampling was used and data were collected until saturation was reached. This was evaluated through reflexive journaling of the primary interviewer and concurrent data analysis and collection.¹¹ Semi-structured focus groups ranging from two to six participants were held giving a total of twenty-four participants (six men and eighteen women) to reach data saturation. Three participants were living with primary progressive MS, two with secondary progressive MS, and nineteen with RRMS.

Data Collection and Analysis

Data collection and analysis were inductive and iterative. Two of the researchers (SJD and KEM) conducted the focus groups. A semi-structured interview guide was used (table 3.1). Focus groups were chosen over interviews to allow for group interaction. However, if a participant could not attend a focus group the option for an individual interview was offered. Focus groups were audio recorded and transcribed verbatim off line. Participants were offered the opportunity to review the transcript from their focus group and provide additional reflective information (i.e. member checking). This step of member checking allowed opportunity for both reactive and reflective data collection. Through the member checking process, participants were also offered the opportunity to provide feedback later on the established themes to ensure perspectives were not misrepresented.

The primary author (SJD) used data immersion, transcript reviewing and audio recording to capture nuance. Researchers avoided using formal coding too soon in the

analysis¹⁰ and spent time immersed in multiple readings and reflection of the transcripts and field notes data.¹² Transcripts were then imported into NVivo 11 (QSR International Pty Ltd, Melbourne, Australia) for formal coding and analysis. Three authors (SJD, CS, LH) coded transcripts independently and met to discuss codes and categories to develop themes. Researchers labeled five resulting themes informed by their clinical research perspectives. Senior author (KEM) reviewed all transcripts with themes in mind to check for any bias or contradicting evidence. Importance was given to the iterative process and all the raw data were re-visited again with the established themes to ensure findings were an accurate and credible representation of data.¹³ Triangulation was used both in data generation (member checking of focus group transcripts and reflective accounts) and in the data analysis process (three researchers independent coding). Notes about research and decision-making processes were kept to ensure a thorough research process¹¹ and that the quality and nature of the findings were congruent with the research process.

Table 3.1. Sample Questions from Semi-Structured PwMS Focus Groups

<p><i>What is your number one priority with your health?</i></p> <p><i>Is being physically active/exercising a priority for you?</i></p> <p><i>Are you as currently as active as you would like to be? Why or why not?</i></p> <p><i>What would help you be more physically active?</i></p> <p><i>What would help you stay physically active?</i></p> <p><i>What motivates you to be active?</i></p> <p><i>What do you think would help the overall community of individuals with MS in Saskatchewan engage in more physically active or exercise regularly?</i></p> <p><i>If you could share one message with your health care provider regarding your needs what would it be?</i></p> <p><i>If you could share one message with other persons living with MS regarding being physically active/exercising what would that be?</i></p>

3.4 Results

Four themes highlighting the current priorities and proposed solutions with regards to PA participation were established: 1) Consistent and constant messaging regarding PA; 2) Support throughout disease progression to inform how to be physically active as needs change; 3) Community Programs with expert input that physicians know about and to which they refer; 4) Training for and access to MS specialists.

3.4.1 Theme one: Consistent and constant messaging regarding physical activity

PwMS reported that hearing consistent and constant messaging about PA across HCP was both a priority and a proposed solution to increase PA behaviour. Consistent and constant messaging included a desire to be informed about and encouraged to be more physically active. Participants wanted to be referred to both resources and providers that could be accessed readily and regularly to implement and monitor on-going PA efforts. It was noted that information on being more physically active was often offered as a 'wellness' package including general information about a healthier lifestyle such as vitamin D and stress management in addition to PA. Overall, a desire for more specific information and support from primary HCP on implementing PA was expressed.

Consistent messaging in this theme also represents participants' expressions of being overwhelmed with trying to self-navigate resources about PA for MS such as through internet searches. Participants reported inconsistency in the variety of information available online and a lack of individualized options. A solution suggested was to have one website that contains localized information relative to an individual's ability and current PA level. *P6: "I'm exhausted and overwhelmed trying to find what I should be doing that I just give up."*

The constant messaging component of this theme reflects participants' desires for HCP to more frequently and consistently promote PA. Constant messaging was also connected to the perception of needing more time with an expert to make changes, rather than just being told to make them. A proposed solution included being routinely asked at annual follow up visits about the details of current PA. Participants suggested that this would give the opportunity for HCP to provide additional support or resources as needs change, as well as holding individuals living with MS more accountable to being physically active. *P11: "Making it a part of a check up, just like weight, and blood pressure, assessing how we are moving and asking how active we have been."* Another proposed solution was to emphasize the importance of PA early in disease course so that PwMS could make it a habit before disease progression increases barriers to being PA.

Constant messaging as a theme further captures the notion that in order to have a program to which one can adhere, that allows one to maintain PA consistently in the face of such a variable disease. It requires having options on how to be physically active. Participant reported solutions such as having affordable, monitored and expert-informed community programs that HCP know about and refer participants to. Also having PA options such as home

program that utilize existing technology to help implement programs in a way that provides choice and minimizes access barriers. Participants suggested that having a variety of individualized programs might facilitate adherence to a routine of being PA. Allowing one to choose which PA option to do based how they are feeling that day, might facilitate committing to the habit of being regularly active, but with the relief of modifying it as needed. *P3: "In dealing with my MS it can be so overwhelming sometimes and I go to all these appointments and I am constantly being tested and pointed out what I can't do, all my limitations. It is so easy to lose sight of what I can do. Being active I have to be reminded about it's importance and that it is an option and I need help to focus on how I can make it an option."*

3.4.2 Theme two: Support throughout disease progression to inform how to be physically active as needs change

Numerous participants reported seeing only their neurologist and family physician for their MS care. PwMS want to be better informed by their primary HCP about the variety of professionals available and might be of benefit for their care. Having options besides just medication at initial diagnosis was seen as a priority. After diagnosis, having a follow up or an education session dedicated to creating a plan of care and providing a resource and/or referral to possible programs and MS PA specialists was a proposed solution. *P1: "I didn't even know that there was such a thing as a physiotherapist that could help me with my MS and being active."*

PwMS want on-going support to navigate the functional limitations that come with disease progression as well as strategies to deal with fluctuations in symptoms. Participants were also hopeful about the role PA might play in this. Being able to have a management approach and seeing someone when you are feeling good to promote ways to keep feeling good, as well as having options for when you are at your worse was desired. *P21: "Being able to have some access to someone to be able to modify your activity to match needs in real-time. That would be ideal."*

P13: "In my case, all the emphasis has been on me to look for stuff, to be motivated, to ask "how is it going with my physical activity?" Which is not very good... And I think for a lot of people it's like that. That would be a solution – have someone work through that stuff with you."

With fatigue and daily fluctuations in symptom severity being a major component of MS, participants consistently highlighted the reality of having to prioritize activities and commitments based on energy levels. Participants emphasized that supporting persons living

with MS requires an understanding of unique components of MS, such as fatigue. Methods of support that could help relieve the burden of or the need to put in any extra energy to create opportunities to be active were desired. A lack of on-going support was linked to a feeling of being left to self-navigate, which increased the energy currency needed to be active.

Participants expressed that a solution cannot be complete unless it considers the support required to manage everyday life. Increasing PA is not separate of being able to manage the stress of the disease and other life commitments. Participants emphasized that solutions to change PA behaviour require a holistic approach recognizing the complexity of the situation. Financial cost was mentioned as well and similar to the support for energy – if individuals with MS have support to help them keep working then financially participating in PA may not be as limiting. *P3: "I have to prioritize, not just time, but energy. The energy currency."*

P4: The energy is currency.

P3: That's right, yeah. It's like energy conservation is what I call it. Every day, so it's – I can never forget that I have MS just because of that."

Depleted energy from being active could be seen as selfish. *P11: "If I am exercising it means I'm not doing something else in my day and I have to plan for that"*

Participants expressed that being too tired to fulfill other commitments such as making dinner because they were physically active can take a negative toll on relationships and other family roles and responsibilities. It was highlighted by some participants that if the reality is that being physically active is going to exhaust someone then advice on how to structure daily commitments or provide support to unload other less meaningful but perhaps necessary activities (such as cooking). This requires a very individualized approach and supports that are not routinely a part of MS management such as lifestyle counseling.

P14: "I used to be quite active and did a lot of stuff like play football and go to the gym. Now I can't do any of it. Nothing that I used to do, so, no I'm not as active as I'd like to be." This quote demonstrates that those giving support need to be cognizant of what one's definition of being active is. A health care provider can harness this information to help facilitate new perspectives, definitions and options for being physically active as abilities change. For some PwMS, PA options outside of organized sport and exercise programs that can be implemented into one's current situation are needed. This level of support involves a holistic approach to facilitating meaningful change in PA behaviour.

3.4.3 Theme three: Community Programs with expert input that physicians know about and to which they refer.

The suggestion of community programs reflects the priority of PwMS wanting to be physically active. Community programs as a solution to improving care ties into theme two and theme four as community programs could be a potential platform meaningful to PwMS to access specialists and the support they seek throughout disease progression. A community program may allow more consistent and perhaps timely access to the support individuals are seeking. This support can be facilitated by tailoring PA interventions to the changing needs of individuals living with MS. It would give HCP a program to refer to, which might help with the promotion of PA. For PwMS it provides support and accountability, which as mentioned in theme two are priorities.

P21: "You know physical activity is not just for physical people, physically active people. And I guess just modifying it for people that have disabilities. That's a huge thing, so, that's my solution, modify it. Just gives us like ideas on how to do that."

There were a number of participants who were unaware of existing community programs such as those supported by the local branch of the MS Society. However, there were also participants in this study who routinely use these resources and felt that these existing programs were under utilized. Any creation of a new program should consider how to increase awareness of its existence to both PwMS and HCP working with PwMS. Some participants living in rural settings expressed frustration with the lack of resources for them. *P2: "...it's more than knowing we should be physically active, but it's just how can we maintain it? How can those accommodations be out there for us so that we are [active] you know?"*

3.4.4 Theme four: Training for and access to specialists

This theme extends beyond PA, to include overall clinical care, lifestyle support, and access to research. Participants expressed wanting to be able to take part in more clinical trials, which may be addressed by having more MS specialists. A solution regarding training for PA was to implement a training course for generalists involved in some aspect of community health promotion (Pilates, yoga and fitness instructors, exercise therapists and personal trainers, wellness coaches were examples given) to gain confidence, mentorship and up to date information on evidence, resources and skills to enhance their ability to work with persons living with MS. Further a method to increase awareness of available resources, such as a

contact person or localized website. P6: *"I'm exhausted to begin with by just having MS. I have to do it, I always have to do it, but I'm so tired re-educating every new health care provider I meet"*

'Access to' in this theme captures the idea mentioned previously (theme two) about wanting information about existing options or resources to help manage needs. For those who can afford it, finding a private rehabilitation therapists with expertise in MS is difficult. For publically funded health care providers like family doctors, there were reported frustrations about finding one with expertise in MS, or issues being able to access available public services (e.g. long wait-lists for general rehabilitation services). For participants who were happy with their family doctor, they reported frustrations that others with MS were unable to get into see this family doctor as they were not accepting new patients. It was apparent that participants want more access to experts as well as multi-disciplinary access as part of the publically funded MS clinic and standard of care. A proposed solution for access was integrating existing technologies such as Telerehab, web-based programs and the MS Society website. Participants highlighted that solutions regarding access need to consider the rural distribution of SK's population. Participants acknowledged that services could improve for major centers and in doing so Ministry and Health Authorities should consider how these improvements can benefit rural populations too. P6: *"I really liked the idea about the options specifically for people with MS. Number one in rural Saskatchewan because unless you're in Saskatoon or Regina you're hooped."*

3.5 Discussion

PwMS have a lot to gain from increasing their PA levels, yet less than 20% are physically active.⁶ This study used a qualitative approach to investigate the priorities and proposed solutions from the perspectives of PwMS to address this conundrum. The priorities and proposed solutions in this study tell us that consistent and constant messaging regarding PA and ongoing support throughout disease progression is crucial to emphasize the importance of PA and to inform how to be physically active as individual needs change. Additionally, participants expressed having community programs with expert input, that clinicians are aware of and refer to, along with an increase in the number of and access to trained specialists in MS, could enhance PA behaviour for PwMS.

A lack of motivation does not appear to be the reason for low PA levels for PwMS. Perhaps instead low PA levels are related to a lack of on-going support as the disease progresses. PwMS need and want increased information and on-going support regarding

lifestyle interventions from HCP.^{14,15} This support should include, but must also extend beyond, educational information to change behaviour.¹⁶ PwMS expressed feeling overwhelmed with being left to seek information on lifestyle interventions themselves (e.g. via the internet). HCP need to take ownership of the role they can play here. Health care systems need to be designed to address ongoing interventions in addition to acute components (e.g. relapse, urinary tract infection) of MS and provide opportunities to use behavioural strategies and foster self-management.¹⁷

The desire to be active and need for professional input reported in this study further supports existing international evidence.^{14,15,18,19} A previous study based in America¹⁵ demonstrated that PwMS perceive they are not currently getting adequate health information from generalist HCP. This report is consistent with our findings. Based on this, we propose that solutions offered by PwMS such as increased training for and access to specialists in MS be further explored. A means to implement this knowledge and follow best practice guidelines and recommendations for care such as the Consortium of MS Centers,²⁰ which recommends accurate information from skilled experts, needs to be put into action.

Participants in this study reported still hearing inconsistent messages from HCP on being PA. Exercise being harmful for PwMS is an outdated perspective.²¹ There is evidence as early as the year 2000; for example, a large-scale (n=930) study showed the need to improve messaging for PwMS with regards to increasing PA behavior.²² Backed by strong and growing evidence since then, increasing PA is found to be safe²³ with numerous health benefits²⁴ and should be a prioritized intervention in MS care.²⁵ Similar to results of a recent review¹⁹ showing mixed-messaging from HCP on PA, our findings emphasize that both communication and access to specialists should be an essential priority in improving MS care. These findings further document the desire PwMS have for accessing HCP with up- to-date information on MS best practice, which may be addressed with specialist training. HCP may not perceive themselves as having a role in this, which might also be addressed by improved communication and specialist training.

Successful management of MS especially the chronic disease components requires improved communication. Communication is essential to all approaches that are centered on collaborations among all types of HCP across the care continuum.²⁶ The difficulties with communication in health care are not unique to MS, however, a system that facilitates increased awareness of existing providers and resources would greatly enhance MS care.

Reasons for communication issues include systemic complexity, time constraints and poor patient recall.²⁷ Poor communication plays a significant role in missed prevention opportunities²⁶ and high-quality communication between care team members and patients has been shown to have a positive influence on patient health outcomes.²⁸

Identifying and implementing programs to improve communication can drive better health outcomes.^{29,30} Integrating the use of existing technology as recommended by participants in this study may support attempts to improve communication and coordinate care. Technology may also help to address access issues and service rural and remote populations. Canada has one of highest rates of MS in the world and also a low population density.³¹ Solutions to improve MS care cannot overlook rural and remote access. Innovative use of technology should be considered and potentially applied to both rural and urban environments in the interest of improved PA behaviour and better healthcare overall. Rural and remote living may have unique considerations about which HCP need to be cognisant to develop care plans and resources appropriate to the environmental realities.

The variety in methods of on-going support and types of community resources suggested as proposed solutions for improving PA behaviour by participants in this study highlight that there is not a 'one size fits all' approach. Holding individuals with MS accountable and giving tools to self-monitor were consistently mentioned. These are BCS. This fits with research suggesting that efforts to increase PA for PwMS should incorporate the use of BCS.³²⁻³⁴ This also hints that this may not routinely be done in practice, another knowledge to practice gap in the management of MS. Based on proposed solutions from this study BCS that warrant further investigation include planning, feedback, monitoring and support.³⁵

End users need to come together to make meaningful change and PwMS are an important voice in this matter. If we want to improve PA in the management of MS it is bigger than just educating – it's about impacting service delivery including incorporating BCS, enhancing resources including access to specialists, and implementing a better means of communicating. Integrated knowledge translation (iKT) is a collaborative approach where all stakeholders come together to investigate a problem and create and implement a solution.³⁶ Taking an iKT approach to the development, implementation and on-going evaluation of a provincial care pathway may address the priorities of PwMS found in this study. Our findings further support recommendations of a recent provincial advisory panel report highlighting that SK does not have a provincial, standardized care pathway for MS in place.³⁷ Further, knowledge

translation has been identified by experts in the field as a research priority for PA and MS.³⁸ Taking an iKT approach facilitates the creation of meaningful and relevant solutions to end-users.³⁶ An iKT approach has built-in problem solving opportunities to facilitate the implementation and further evaluation to ensure solutions are doing what they intend to.

Limitations and future research:

The sample in this study is representative of the demographics of the larger MS population (ratio of female:male and relapse remitting:progressive disease course) and although an appropriate size for qualitative methodology, the findings may have limited generalizability. Results of this should be used to inform the development of studies designing and implementing PA interventions for PwMS. This study did not sample based on PA levels of participants (e.g. inactive, contemplating, currently active but wanting to increase, currently active), which may have limited insight of unique needs based on PA levels.

Based on the findings in this study, future research investigating methods of improving communication across care contexts is warranted. Innovative ways to build on existing resources to improve access and on-going support to provide specialized, localized and individualized care are needed. This should be done in conjunction with consideration of ways to support HCP to provide the support for PwMS with regards to chronic disease management in a rural and remote context. Future research should take an iKT approach to further explore the proposed solutions offered in this study.

Listening to and learning from the lived experience can provide substantial insight into the local and immediate needs of PwMS. Solutions driven from the individuals that interventions are meant to effect will hopefully enhance uptake and effectiveness of interventions. Meeting the needs of PwMS with an idea of their priorities allows collaborative and meaningful change. Understanding the lived experiences of PwMS is essential if HCP are to provide appropriate support to influence PA behaviour.

Clinical Practice Points:

Persons living with multiple sclerosis want a more consistent, integrated, supported and holistic approach to the management of their health condition. Consistent and constant messaging regarding physical activity and ongoing support throughout disease progression is crucial to emphasize the importance of physical activity and to inform how to be physically active as needs change. Persons living with multiple sclerosis propose making use of existing technologies and improving communication regarding available resources as well as increasing

the number of resources to facilitate wellness as meaningful solutions. Understanding the experiences of persons living with multiple sclerosis is essential if health care providers are to provide appropriate support to influence physical activity behaviour.

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CHAPTER 4: Informing the training of health care professionals to implement behaviour change strategies for physical activity promotion in neurorehabilitation: A systematic review

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4.1 Abstract

Background: Initiatives to increase PA are most effective when combined with BCS. However, this is not routinely done and perhaps can be attributed to HCP' lack of confidence and understanding of how to best apply BCS. This review aimed to identify and synthesize the existing literature describing methods used to train HCP to deliver BCS for PA promotion for individuals living with neurological conditions.

Methods: This review followed the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines. Eight databases were searched for articles describing how HCP were trained on BCS targeting PA and/or exercise for neurological pathology. Two researchers independently screened abstracts and used third party consensus when needed. Studies must have described the planning/implementation of BCS targeting PA in adults with neurological disorders, with interventions delivered by a HCP. A data extraction table based on the study objective and the Cochrane Consumers and Communication Review Group's data extraction template was used. Risk of bias was assessed using the Quality Assessment Tools for Quantitative and Qualitative Studies. Included studies were also evaluated using the Workgroup for Intervention Development and Evaluation Research (WIDER) recommendations for reporting behaviour change intervention content. Extraction and evaluation of risk of bias were completed independently by two researchers. Data were synthesized according to a who, what, when and how approach.

Results: The search yielded 2,616 articles after duplicates removed, with thirteen articles, representing eight unique interventions in individuals with spinal cord injury, stroke, MS and Parkinson's disease, included. Methodological quality ranged from strong to weak. Methods used to increase HCP knowledge and use of BCS were heterogeneous. Common training features included multiple resources, multiple sessions, expert input and ongoing support, but

a lack of evaluation of training effectiveness. The BCS were based on SCT in seven interventions. PTs were the most common HCP trained.

Conclusion: There was considerable variety in how HCP were trained to use BCS and a lack of evaluation of training effectiveness. Future work should include more description of the content and structure of HCP training and a direct measure of effectiveness. Researchers should consider implementation strategies during development and reporting of BCIs.

Keywords: neurorehabilitation, complex interventions, behaviour change strategies, physical activity, implementation, translational research

4.2 Introduction

Increasing one's PA, as part of daily life or through a structured exercise program, has numerous benefits. In individuals with a neurological pathology, there is the potential for exercise to influence neurotrophic, neuroprotective and disease modifying effects,¹⁻³ in addition to providing general health benefits. Despite the benefits, individuals with neurological disabilities are far less active than recommended.^{4,5} Neurological pathology makes engagement in PA more challenging due to physical limitations (e.g. balance impairments) and potential mental challenges (e.g. cognitive impairment). Additional measures are required to successfully increase one's long term engagement in PA.^{5,6}

While the details of the optimal dose and intensity of exercise are still being explored, there is a general consensus that any increase in PA can be an asset. Efforts to increase PA levels should be an integral part of neurorehabilitation.⁷ Simply educating clients about the importance of being physically active is not sufficient to initiate and maintain increased engagement in PA on a regular basis.^{6,8} A current theme in the literature is that a successful increase in exercise and PA in neurological populations should include BCS.^{9,10} A BCS can be defined as a technique designed to specifically address one or more psychological determinants of behaviour.¹¹ BCS make up the active components used in BCIs. Effective strategies to address PA behaviour in neurorehabilitation include tailored counseling such as goal setting, planning, monitoring and feedback.¹² Best practice guidelines and systematic reviews recommend that an initiative to increase PA is most effective when combined with BCS.^{9,12-14} However, this is not routinely done¹⁵ and perhaps can be attributed to HCP' lack of confidence and understanding in applying BCS.¹⁶⁻¹⁹

This systematic review was inspired by the need to go beyond simply suggesting that the promotion of exercise should occur in tandem with BCS. Instead this review acknowledges the need to move toward clinical implementation. Is there insight in the literature that could inform the content and structure of a program to increase HCP' knowledge, confidence and use of BCS to promote PA for individuals with neurological conditions? The aim of this review was to identify and synthesize the existing literature that describes the methods used to train HCP to deliver BCS for PA promotion in neurological populations. We examined how prior behaviour change intervention studies have trained HCP in delivering the BCS used in the interventions. Information regarding the who, how, what and when of the HCP interventionist training was sought to inform future training programs for HCP for PA promotion in neurological populations.

4.3 Methods

Search Strategy

This systematic review was conducted in accordance with the PRISMA guidelines.²⁰ The protocol for this review was not registered. Eight electronic databases were searched from inception to September 11, 2017: Medline (OVID), PubMed, EMBASE, PsycINFO, CINAHL (Cumulative Index to Nursing and Allied Health Literature), Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, and ProQuest Dissertations & Theses Global.

The search strategies were developed in collaboration with an Information Specialist (MP) utilizing a modified PICO (population, interventions, comparators, outcomes) approach which included: HCP (population) trained to implement BCS (intervention) to increase PA (outcome) in a neurological population. No comparator was used. In the search strategies, the intervention was qualified more specifically to include: interventions delivered by HCP to affect participants' PA and exercise; determining the competencies HCP need to use BCS effectively, and determining how the evidence, knowledge and research in the BCIs field was being translated into clinical practice. Subject headings were used as appropriate for each database, as well as free text terms relevant to the topical concepts. No limits were applied. The full Medline search strategy is provided in Appendix C.

For the sake of this review, the neurological conditions most commonly seen in adult neurorehabilitation were included: stroke, brain injury, MS, Parkinson's disease, spinal cord injury, post-polio syndrome, Guillain-Barre syndrome.²¹

Data Extraction

A research management tool (EndNote, Clarivate Analytics, New York) was used to de-duplicate the search results. Title and abstract screening then occurred simultaneously. All screening was carried out by two authors (SJD and KC), using predefined inclusion and exclusion criteria. In the case of differing results concerning the inclusion of a title or abstract, a third researcher was consulted to make the final decision (KEM).

Inclusion criteria were as follows:

The study included the planning and/or implementation of a BCI that:

- 1) targeted individuals with neurological disorders who were aged 18 years or greater;
- 2) was delivered or supervised by HCP, defined as an individual who provides preventive, curative, promotional or rehabilitative health care services in a systematic way to people, families or communities including health experts;²² and 3) targeted promotion of PA and/or exercise. Exclusion criteria included animal studies, conference abstracts, protocol papers without the corresponding intervention study published, and any study in which the BCS targeted individuals with non-neurological disorders (e.g. chronic fatigue, fibromyalgia, obesity, rheumatoid arthritis). Isolated peripheral nerve injuries (such as Bell's Palsy or carpal tunnel) or disorders with predominantly biochemical vs. structural involvement (e.g. chronic pain, epilepsy) were also excluded.

Articles that met or were suspected of meeting the inclusion criteria were included in the full text review. In addition to the inclusion criteria listed above, articles must have described how the interventionist was trained to be included in the full analysis. To avoid exclusion of any potential study too early, this inclusion criterion was not implemented until the full article screen. When studies stated further information about the HCP training was available upon request, we requested the information and included any information provided to us in our decision to include or exclude the article. Each article was reviewed by two researchers (SJD and KC) independently to confirm or refute inclusion, with the final decision being made through discussion with third reviewer (KEM). One researcher (SJD) also scanned the reference lists of included articles to identify any additional relevant articles.

A data extraction template was created based on our study objective and informed by the Cochrane Consumers and Communication Review Group’s data extraction template. There were no studies returned in the search that directly investigated training for HCP in BCS for PA in neurological populations. Data were extracted from studies that described how the HCP interventionists were trained as part of the description of the BCI. The data extraction table (see Appendix C) was completed separately by two authors (SJD and KC). Any discrepancies were resolved through consensus. Following extraction, the data were organized according to a who, how, what, and when approach (see Table 4.1) for description of the method(s) used to prepare the HCP interventionists in the studies on how to deliver the BCS.

Table 4.1 Who, how, what and when approach to data extraction

WHO	<i>Who was the interventionist? Who did the intervention target (and number of participants)?</i>
HOW	<i>How was the interventionist trained to implement BCS, including what resources were used in training and who did the training? How was training directly or indirectly evaluated?</i>
WHAT	<i>What BCS were used in intervention that interventionist had to be trained in? What theory was intervention based on? What were the relevant results and conclusions?</i>
WHEN	<i>When was training implemented relative to intervention and training length? When was on-going support provided, if any, to interventionist and what was it? What was the length of study and timing of outcome measures? What was the frequency of intervention?</i>

When extracting data from full texts, the questions listed on the right were addressed

Risk of bias

The risk of bias for included quantitative studies was assessed using the Quality Assessment Tool for Quantitative studies.²³ This tool yields an overall methodological rating of weak, moderate or strong. The tool covers eight sections including: selection bias, study design, confounders, blinding, data collection methods, withdrawals/dropouts, intervention integrity, and analysis. The Quality Assessment Tool for Quantitative studies has been previously evaluated for content and construct validity, and inter-rater reliability.²⁴ For the two included studies that used qualitative methodology, a tool comparative to that used for the quantitative studies was chosen. The Quality Assessment tool for Qualitative Studies²⁵ evaluates five components including: research aim; methods and design; sampling; data collection and

analysis; and results, discussion, and conclusions. No studies were excluded based on the results of the quality assessment. A risk of bias analysis was completed independently by two authors (SJD and KC) with input from a third author to resolve disagreements (SM).

Quality of BCI Reporting

The Workgroup for Intervention Development and Evaluation Research (WIDER) established recommendations to improve the reporting of BCIs.²⁶ WIDER recommendations provide a framework for the reporting of essential components of BCIs in order to facilitate understanding, replication, and further development of reported interventions. As part of the recommendations, a checklist to assess the quality of reporting of BCIs was developed.²⁷ The checklist considers intervention description, including development, what BCS were used and causal processes involved in intervention, access to the intervention manual and/or protocols, and description of control conditions where appropriate. It was used to assess the quality of BCI reporting in this review. The checklist was completed independently by two researchers (SJD and KEM) with the final ratings established through consensus.

4.4 Results

The results from the database searches and corresponding screening stages are outlined in Figure 4.1. The search yielded 2,928 abstracts. After de-duplicating, 2,616 abstracts remained. A further 2,557 abstracts were deleted through title and abstract screening, leaving 59 articles for full text review. Although no studies were found that directly investigated how to train HCP in BCS for PA in neurological populations, ultimately 13 articles met the inclusion criteria. Common reasons for exclusion were as follows: 1) the article did not mention how the HCP was trained to implement the BCS, 2) the BCS was delivered using technology (such as an app or web program) rather than a HCP, 3) the BCS targeted a behavior other than PA (such as medication adherence), or 4) the BCS targeted participant populations that were not primarily neurological (mainly rheumatic diseases, diabetes, heart disease, urinary incontinence).

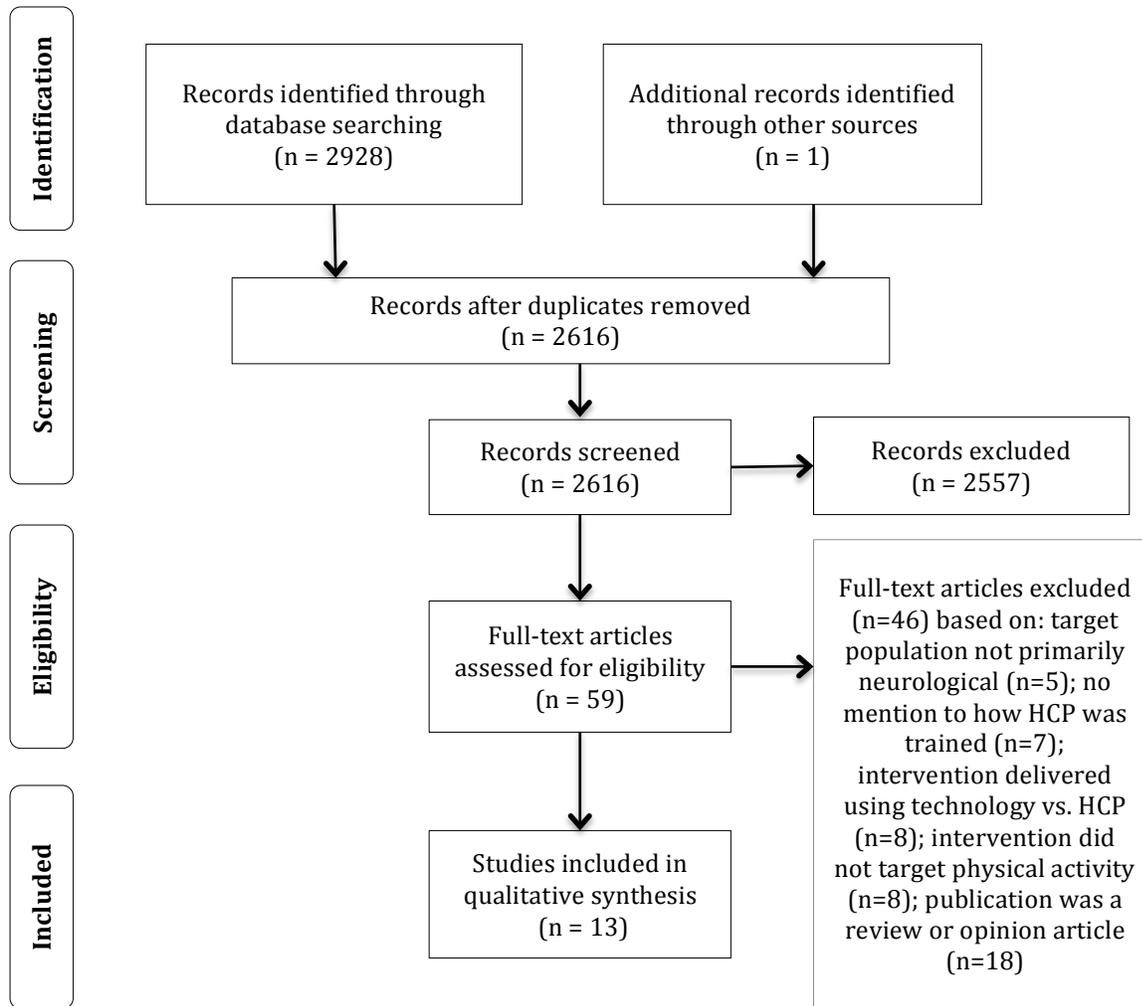


Figure 4.1 PRISMA Flowchart.

Out of the thirteen included articles, a total of eight unique interventions were presented (see Table 4.2 for description). Some publications described different stages (e.g. protocol or intervention development, intervention implementation) or aspects (e.g. primary vs. secondary results, or evaluation of the implementation process) of the same study, while one article contained a report on two separate interventions.²⁸

Table 4.2 Summary of the 8 interventions, including ‘who’ was trained and ‘who’ received training

Type of Study	Intervention Description	WHO	
		Target Population	HCP Interventionist
GMCB (Group Mediated Cognitive-Behavioral Training)			
Pilot Feasibility Intervention Study; Results: Brawley et al., 2013 ³⁸	- Counseling intervention based on SCT & use of group dynamics - Group is an agent for change to facilitate self-management and foster long term adherence of PA	- SCI - Participating in supervised PA - n=10	- Exercise specialist - n=1
*Motivational Counseling			
Pilot Intervention Study; Results: Latimer-Cheung et al., 2013, ²⁸ <i>Part A</i>	- Single counseling session using motivational interviewing to strengthen social cognitions associated with leisure time PA	- SCI - Not currently active, but intend to be more active - n=7	- Graduate students in exercise psychology - n=2
“ParkFit”			
RCT; Protocol: van Nimwegen et al., 2010, ³² Results: van Nimwegen et al., 2013, ³³ Evaluation of intervention implementation: Speelman et al., 2014 ³¹	- Multifaceted behavioural and exercise program to promote PA for PwPD - Emphasis on PA coaching and goal setting	- PD (mild-moderate) - Sedentary - n=299	- PTs - n=154
*Peer-Mediated Intervention			
Pilot Intervention; Results: Latimer-Cheung et al., 2013, ²⁸ <i>Part B</i>	- Peer-mediated home intervention designed to address exercise barriers and increase self-efficacy and strength training behaviour	- SCI - Not currently active, but intend to be more active - n=12	-Exercise specialists - n=2
“PRACTISE” (Promoting Recovery of the Arm: Clinical Tools for Intensive Stroke Exercise)			
Participatory Action Research Approach; Development of Intervention: Connell et al., 2015, ³⁹ Knowledge Translation of Intervention: Connell et al.,	- Complex behaviour change intervention that aims to increase upper limb use in Stroke rehabilitation - Intervention includes techniques to change HCP behaviour regarding addressing the upper limb in rehabilitation - Includes a tool-kit to change clients’ post-stroke activity behaviour with regards to upper	- Stroke - Upper limb involvement -Described development of intervention; no PwCVA participants enrolled	- PTs, OTs, Rehabilitation assistants - n= n/r

2016 ⁴⁰	limb use		
“Project GEMS” (Guidelines for Exercise in Multiple Sclerosis)			
Feasibility RCT; Protocol: Adamson et al., 2015, ²⁹ Results: Learmonth et al., 2016 ³⁴	- Home based physical activity program (DVD) paired with a SCT based behaviour change program - Delivered via educational material (manual, log book and newsletters) and one-on-one online behavioural coaching	- MS (mild-moderate) - Non-exercisers - n=25	-Exercise specialists - n= n/r
“Step It Up”			
Pilot RCT, Protocol: Coote et al., 2014; ³⁰ Primary Results: Hayes et al., 2017; ³⁵ Secondary Outcomes Results: Coote et al., 2017 ³⁶	- Exercise program consisting of a self-monitored aerobic component and a group strengthening class, plus a SCT-based multifaceted behaviour change intervention - delivered through group sessions and coaching calls	- MS (mild) - Sedentary - n=32	- PTs - n=8
Stroke Self-Management Program			
Pilot RCT, Results: Damush et al., 2011 ³⁷	- Stroke specific self-management program centered around SCT and enhancing clients’ self-efficacy to engage in self-managed healthy lifestyle activities, including PA, to improve health related quality of life - Delivered using telephone coaching and follow-up calls	- Stroke (one month post) - No detail - n=33	- Nurse, Physician assistant, Graduate student social science - n=3; 1 of each

*n= number of participants or HCP, n/r= not reported; PA= physical activity; PD= Parkinson’s disease; PwCVA= Persons living with cerebral vascular accident; PwPD= Persons living with Parkinson’s disease; RCT= randomized controlled trial; SCI= spinal cord injury; SCT = Social Cognitive Theory; *same publication but two different interventions.*

Risk of Bias

Four articles were not included in the risk of bias analysis.²⁹⁻³² One of these articles evaluated the implementation of a BCI³¹ and the other three articles were protocol papers.^{29,30,32} All four of these articles corresponded to one of the eight included interventions, which were represented in another included article³³⁻³⁵ for which the risk of bias analysis was completed. For example, the risk of bias of protocol papers was not evaluated if the results of the study were published; the risk of bias of the completed studies was evaluated instead. Only

one of the included interventions was a large scale full sized multi-centered, double blinded randomized controlled trial.³³ Using the Quality Assessment Tool for Quantitative Studies (n=7), three studies were of high quality rating,³⁴⁻³⁶ two were rated moderate,^{33,37} and two were given a weak rating^{28,38} (see Table 4.3). Based on the Quality Assessment Tool for Qualitative Studies (n=2), the two qualitative studies^{39,40} were ranked a 5, the highest rating.

Table 4.3 Risk of Bias Assessment

Author (Year)	<i>Quality Assessment Tool for Quantitative Studies</i> rating	<i>Quality Assessment Tool for Qualitative Studies</i> rating	Author (Year)
Learmonth et al., 2017; ³⁴ Hayes et al., 2017; ³⁵ Cootes et al., 2017 ³⁶	Strong	5	Connell et al., 2015; ³⁹ Connell et al., 2016 ⁴⁰
Damush et al., 2011; ³⁷ van Nimwegen et al., 2013 ³³	Moderate	4	None
		3	None
Brawley et al., 2013; ³⁸ Latimer-Cheung et al., 2013 ²⁸	Weak	2	None
		1	None

Quality of Behaviour Change Intervention Reporting

None of the included interventions met all four of the WIDER Recommendations (see Table 4.4). It is important to recognize that some studies reported more details than others, as made known by the sub-recommendations criteria. When viewing Table 4.4, the number of boxes with an x for each intervention indicates the number of WIDER principles met. Most articles did not provide a detailed description of the HCP interventionists.

Table 4.4 WIDER Recommendations for Reporting BCIs

Intervention	#1 Detailed Description of Intervention								#2 Clarification of Assumed Change Process and Design Principles			#3 Access to Intervention Manuals/Protocols	#4 Detailed Description of Active Control Conditions							
	Interventionist	Recipient	Setting	Mode of Delivery	Intensity	Duration	Adherence	Intervention	Intervention Development	Change Techniques	Causal Process		Interventionist	Recipient	Setting	Mode of Delivery	Intensity	Duration	Adherence	Intervention
GMCB ³⁸		x	x	x		x	x	x	x	x	x	Manual available through author contact	no Control							
Motivational Counseling <i>Part A</i> ²⁸		x		x		x	x	x		x	x	Manual available online	no control							
ParkFit ³¹⁻³³	x	x		x		x	x	x	x	x		Protocol paper published; no mention of access to manuals	x	x		x	x	x	x	x
Peer-Mediated Intervention <i>Part B</i> ²⁸	x	x	x	x				x	x		x	Manual available online	no control							
PRACTISE ^{39,40}	x	x	x	x				x	x	x	x	Manual available online	no Control							
Project GEMS ^{39,34}		x	x	x	x	x			x	x	x	Protocol paper published; no mention of access to manuals	wait-list control group							
Step it Up ^{30,35,36}		x		x		x	x	x			x	Protocol paper published; no mention of access to manuals		x		x		x	x	x
Stroke Self-Management Program ³⁷		x	x	x		x	x	x	x	x		Manual available through author contact		x	x	x			x	x

Description of Training of HCP to Deliver Behaviour Change Intervention

Who

There were a variety of HCP trained as interventionists in the different studies (see Table 4.2). Two of the eight BCI used more than one type of HCP as their interventionist.^{37,39} A total of seven different HCP were trained to implement BCS (PT, OT, rehabilitation assistant, physician's assistant, nurse, exercise specialists, and graduate students in exercise psychology or social science). PTs and exercise specialists (personal trainers, kinesiologist, exercise therapist) were the only interventionists to appear in more than one BCS training initiative. All articles stated that the interventionist was a specialist with regards to the study's target population; however they were not necessarily an expert with regards to PA/exercise prescription.

Three of the eight BCI targeted individuals with spinal cord injury,^{28,38} two targeted individuals with stroke,^{37,39} two targeted individuals with MS,^{34,35} and one targeted individuals with Parkinson's Disease.³³ The PA levels of participants varied, from sedentary,³³⁻³⁵ to not active but with intentions to be active,²⁸ to currently active at least three times/week.³⁸ PA levels of participants were not specified for two interventions.^{37,39} All studies specified that participants had no cognitive impairments.

How

Compared with who was trained, there were more similarities with how the HCP were trained (see Table 4.5). Even though methods varied, some common features include multiple resources, multiple training sessions, expert input and ongoing support. With respect to the resources used, all BCIs included a manual for the interventionist. Four manuals explicitly described the inclusion of relevant theoretical knowledge^{33,35,37,38} and three manuals provided instruction for behavioural coaching sessions.^{33,34,38} Other resources included websites,^{28,33} videos,²⁸ coaching scripts^{29,33} and workbooks to guide HCPs on specific elements of behavioural change.³¹ Resources appeared to include content on population specific benefits and risks of PA, information about behaviour change theory and process, and user-information regarding the tools of the specific intervention (e.g. ParkFit³³ program used a health contract and activity monitor). In-person training focused on the skills needed to implement the BCS for each intervention (e.g. goal setting, problem solving, action planning).

Three of the BCIs explicitly mention that a researcher or an expert in BCS delivered the in-person training for the HCP.^{28,34,38} Other methods of HCP training included the use of a group activity to develop the intervention,³⁹ and rehearsing the intervention with peers.²⁸ Ongoing support for the HCP was provided in all included BCI, most likely as part of the research process. The type of ongoing support varied, but included continued access to the research team for HCP as needed, structured follow-up from researchers with HCP, pre-arranged meetings throughout intervention duration, and audited sessions including feedback for the HCP. More uniquely, the PRACTISE program³⁹ involved HCP working with researchers to develop the intervention.

No study directly evaluated the effectiveness of the HCP training in BCS. Instead evaluation of the effectiveness of HCP training could perhaps be inferred indirectly through evaluation of the change in behavior of the participants with neurological pathology (e.g. perceived or actual benefits) (see Table 4.5 and Appendix C). One possible exception was the evaluation of implementation of the ParkFit study,³¹ in which the authors evaluated the perceptions of the HCP experience with the BCI using semi-structured qualitative interviews and a self-administered questionnaire. Only 1% of the HCP (PTs for this intervention) felt that their knowledge of BCS was not sufficient at the completion of the study. All included interventions did incorporate either a qualitative (e.g. researcher audit of intervention^{33-35,37,39}) and/or a quantitative measure of treatment fidelity (e.g. checklist or questionnaire^{28,38}). The output of the PRACTISE BCI development study³⁹ emphasizes the importance of intervention fidelity by including an audit resource as part of the intervention toolkit. However, with the lack of detailed reporting on findings of fidelity measures and with variability in how intervention fidelity was accounted for no consensus on which training technique is best at ensuring or increasing intervention fidelity.

Table 4.5 Summary of details provided on HCP training to deliver BCS intervention

HCP Interventionist	Person providing training	How was HCP trained	How was training evaluated **
GMCB (Group Mediated Cognitive-Behavioral Training)³⁸			
Exercise specialist; n=1	experienced counselor with expertise in GMCB	<ul style="list-style-type: none"> - in person training, length n/r - used an interventionist manual with material tailored for active individuals with SCI - training topics included lesson plans, counseling tasks, GMCB theory, and overview of participant material - manual and intervention resources available from first author contact 	<ul style="list-style-type: none"> - indirectly through measuring changes in participants' social-cognitive variables and PA levels - more directly through measuring intervention fidelity and participants' and HCP' perceptions of content, delivery and group environment
Motivational Counseling²⁸			
- Graduate students in exercise psychology; n=2	not reported	<ul style="list-style-type: none"> - in person training, length 1 day motivational coaching course - used an interventionist manual - training focused on how to evoke client's own motivation to change, determining willingness to change, eliciting values, building rapport, resolving uncertainty about change, and intervention specific BCS - manual and intervention resources available online 	<ul style="list-style-type: none"> - indirectly through measuring changes in participants' social-cognitive variables and PA levels - more directly through measuring intervention fidelity and acceptability
"ParkFit"³¹⁻³³			
PTs; n=154	not explicitly reported but suggestive of authors (with expertise in exercise, behaviour	<ul style="list-style-type: none"> - in person training over 3 sessions, length n/r - used an interventionist manual and coaching scripts - training topics included education on PA for PwPD, SCT, TTM and application to 	<ul style="list-style-type: none"> - indirectly through measuring changes in physical activity participation, function, symptoms and quality of life - more directly through

	change and PD)	behaviour change process, intervention specific BCS, discussion on content of all intervention material (participant workbook, accelerometer and website), and how to cope with differences in character between HCP and participants - manual and intervention resources available from first author contact	interviews with participants and HCP, and evaluation of intervention implementation ³⁰
Peer-Mediated Intervention²⁸			
Exercise specialists; n=2	researcher with expertise in health behaviour change, exercise and SCI	- in person training, length n/r - included practice and rehearsal with physically active individual with SCI involved as peer in intervention delivery - used an interventionist manual - training topics included SCT, benefits of PA, strength training exercises and intervention specific BCS - manual and intervention resources available online	- indirectly through measuring changes in participants' social-cognitive variables and PA levels - more directly through measuring intervention fidelity and acceptability
"PRACTISE" (Promoting Recovery of the Arm: Clinical Tools for Intensive Stroke Exercise)^{39,40}			
PTs, OTs, Rehabilitation assistants; n= not reported	HCP were part of the intervention development process with researchers with expertise in behaviour change, exercise and stroke	- In person team meetings, length n/r - On-going support - BCW guided development of behaviour change intervention - Intervention manual available online	- HCP interventionists were part of PRACTISE development ³⁸ - More directly measured audit tool and interviews ³⁹

“Project GEMS” (Guidelines for Exercise in Multiple Sclerosis)^{29,34}			
Exercise specialists; n= not reported	reports training was “from experts in behaviour change for PA”	<ul style="list-style-type: none"> - in person training; length n/r - on going weekly meetings - used a training manual and standardized scripts - training topics included SCT and its application, discussion on content of all intervention material (newsletter, exercise DVDs, participant manual and log book, pedometer) - manual and intervention resources available from first author contact 	<ul style="list-style-type: none"> - indirectly through measuring changes in participants’ PA participation, function, symptoms, quality of life and social-cognitive variables - more directly through measuring acceptability and feasibility
“Step It Up”^{30,35,36}			
PTs; n=8	not explicitly reported but suggestive of authors (with expertise in exercise, behaviour change and MS)	<ul style="list-style-type: none"> - in person training; length 1 day - ongoing support and additional training available as needed - authors note “further training and support may increase the success of the intervention in the future” - manual of operating procedures - training topics included exercise intervention components, educational control materials, SCT theory and relevant BCS needed for SCT-based component of intervention - manual and intervention resources available from first author contact 	<ul style="list-style-type: none"> - indirectly through measuring changes in participants’ social-cognitive variables, function, symptoms, and PA level - more directly through qualitative analysis of participant experience and measuring intervention fidelity: an independent person to intervention compared ad-hoc video analysis of HCP intervention delivery to intervention operating manual
Stroke Self-Management Program³⁷			
Nurse, Physician assistant, Graduate student social	not reported	<ul style="list-style-type: none"> - in person training; length 18 hours total - interventionist manual - training topics included 	<ul style="list-style-type: none"> - indirectly through measuring intervention impact on quality of life, self-management and self-

science; n=3; 1 of each		SCT, chronic disease self-management, information on local support groups, intervention material and intervention specific BCS - manual and intervention resources available from first author contact	efficacy - more directly through measuring intervention fidelity: at random researcher observed at least one session delivered by each HCP and provided feedback
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BCW= Behaviour Change Wheel; n/r= not reported; PD= Parkinson's disease; PwPD= persons living with Parkinson's disease; SCI= spinal cord injury; TTM= Transtheoretical Model **same publication but two different interventions note 'n' refers to number of HCP trained as interventionists; **for details on specific measurement tools used see data extraction table in Appendix C*

When

The when section was under reported and had the most variability across included interventions. When the training in BCS was applied relative to the start of the BCI was not specified in any study. In contrast, the length of training was described for four of the eight interventions. In the studies that did report the length of training, the units of time used varied (hours, days, sessions) making it difficult to compare. Parkfit³³ included 3 separate sessions, but provided no indication of the time between those three sessions. Two interventions employed one day of training,^{28,35} while one intervention reports using a total of 18 hours for HCP training.³⁷ The training provided in the study by Connell and colleagues³⁹ was delivered over several months, but again, this study was unique in that the HCP were part of the development process.

What

There were a total of five different behaviour change theories and frameworks that the included interventions were based on. Of the eight BCIs, five used more than one theory (see Appendix C). The most commonly used theory was Bandura's SCT (n=7), followed by the Health Action Process Approach (n=3). The Transtheoretical Model was used once.³⁷ The Behaviour Change Wheel and the Behaviour Change Technique Taxonomy version 1 were frameworks used to guide intervention development in one study.³⁹ Some studies had a dominant behaviour change approach (e.g. Motivational Interviewing²⁸ or Group Mediated Cognitive Behavioural intervention³⁸). Others were self-declared multi-faceted behaviour change programs.^{33-35,37,39} All BCIs are by nature complex interventions with multiple active components,⁴¹ and as such a variety of specific BCS were employed across studies with most strategies being used in more than one intervention (see Table 4.6).

TABLE 4.6 BCS Used Classified by the BCTTv1

Intervention BCTTv1 Code⁴¹	GMCB for SCI³⁸	Motivational Counselling SCI²⁸	ParkFit^{31- 33}	Peer- mediated intervention SCI²⁸	PRACTISE^{39,40}	Project GEMS^{29,34}	Step It Up^{30,35,36}	Stroke Self- management Program³⁷
1. Goals and planning								
1.1 Goal setting (behavior)	++	++	++	++	++	+	++	++
1.2 Problem solving	++	++	++		++	+	+	++
1.4 Action planning	++	++	++	++	++	+	++	++
1.5 Review goal(s) (behavior)			++					
1.8 Behavioral contract			++	++	++			++
2. Feedback and monitoring								
2.1 Monitoring of behavior by others without feedback							++	
2.2 Feedback on behavior	++		++	++		++		++
2.3 Self-monitoring of behavior	++		++	+	++	++	++	++
3. Social support								
3.1 Social support (unspecified)	++	++	++	++		++	++	++
3.2 Social support (practical)	++		++		++			
4. Shaping knowledge								
4.1 Instruction how to perform behavior	++		++	++	++	++	++	+

4.2 Information about antecedents		++						+
5. Natural consequences								
5.1 Information about health consequences		++	++	++			++	++
5.4 Monitoring of emotional consequences								++
6. Comparison of behavior								
6.1 Demonstration of Behaviour			++	++		++	++	++
8 Repetition and substitution								
8.1 Behavioral Practice/rehearsal	++		++		++	++	++	++
8.7 graded tasks	+		++		+	++	++	
9. Comparison of outcomes								
9.1 Credible source	++	++	++	++	++	++	++	++
9.3 Comparative imagining of future outcomes		+						
10. Reward and threat								
10.3 Non-specific reward							+	
10.4 Social reward				++				
11. Regulation								
11.2 Reduce negative emotions						+		++
15. Self-belief								
15.3 Focus on past				++			+	++

success								
Reported BCS not in BCTTv1 codes								
Increase positive emotions	++	++		++	++	++	++	++

4.5 Discussion

This systematic review synthesized the available literature on how HCP have been trained to deliver BCS in intervention studies targeted to increase PA in a neurological population. Although no studies directly investigated how to train HCP in BCS for PA in neurological populations, thirteen studies were identified covering eight unique interventions that met final inclusion criteria. To the best of our knowledge no studies exist where the primary intervention was a training program for implementing BCS for HCP working with neurological populations. This review highlights a need for studies that develop and measure the effectiveness of a training program for HCP regarding BCIs to increase PA for neurological populations to move towards clinical implementation of BCS. Extracting from studies that included details of how HCP were trained to deliver PA BCIs, we noted that using multiple resources, multiple training sessions, expert input and ongoing support, seven different types of HCP were trained to deliver a variety of BCS based predominantly on SCT.

The variety of HCP used across the studies leads one to question if there is a professional relevance to how a HCP is trained in BCS. Some studies used more than one HCP as an interventionist without tailoring interventionist training. No conclusions can be made from this review as to whether all HCP are equally equipped to use BCS or if one profession is better positioned than another. PTs were one of the most common HCP involved across included interventions, most likely because they are recognized experts in PA and exercise for individuals with neurological disease or injury.

Similarly, no consensus can be made at this point regarding what specific BCS should be included in a training of HCP working with neurological populations. This could be confounded by a lack of common terminology used to describe BCS. This review extracted information regarding the BCS used in each included intervention based on the Behavior Change Technique Taxonomy (BCTTv1).⁴¹ A training for HCP on BCS may benefit from using consistent terminology and definitions such as those provided by the BCTTv1. Based on included studies, it is suggested that strategies employed should consider a client's current activity level⁴² and be customized to each individual. It is therefore recommended that training of HCP in BCS includes instruction on how to guide BCS selection. Based on the results of this review, some strategies to consider for inclusion in training are detailed goal setting, problem solving, action planning, using credible sources, social support and knowledge shaping techniques. Based on the most commonly used theories in the included studies, training may include education on

SCT and the Health Action Process Approach as key behaviour change theories. It is worth mentioning that the Behaviour Change Wheel used in Connell et al.³⁹ is a potentially useful framework to guide intervention development and selection of BCS regardless of the theory of behaviour change that the intervention is based on.

Only thirteen articles met the inclusion criteria of this review with a primary reason for exclusion being a lack of detail concerning how the HCP was trained. Further, we found that none of the included interventions fulfilled all recommendations provided by the WIDER (see Table 4.4). It is currently not an explicit WIDER recommendation to include a description of interventionist training, but this addition might further enhance reporting. We are in agreement with other authors^{10,27} that behaviour change literature is in need of improved reporting. To improve the implementation and replication of effective BCIs, better methods to specify and report on the 'active ingredients' are needed. Precise details of study interventions are often omitted. As seen in this review, how the HCP is trained to deliver an intervention is rarely described in the level of detail that could inform clinical application.⁴³ A common terminology would be useful, but may not necessarily change reporting.⁴⁴ Even though the WIDER recommendations exist, there is currently no consistently used or recommended guideline to follow for reporting complex BCIs.^{44,45} No studies were found in our search that evaluated either continuing education on BCS for HCP working with neurologic populations or the training of student HCP in BCS. The training of PA promotion and appropriate BCS at the graduate entry level likely exists, but the extent to which it prepares HCPs to implement this knowledge into practice is unknown.⁴⁶ General knowledge about health promotion may not transfer to neurological populations and to the best of our knowledge, no one has studied how to effectively deliver this training specifically for application to neurological populations or to deliver this information in continuing education for practicing HCP working with neurological populations.

BCIs are usually complex and include a variety of components.^{41,47} Perhaps with complex interventions, such as BCS for PA promotion, optimal reporting should include several steps. Four^{33-35,39} of the eight interventions in this review had multiple publications (e.g. protocol, primary/secondary outcomes and/or implementation). It is recognized that trial registration and journals have restrictions on word count, thus, perhaps multiple publications or online supplementary material are necessary strategies for reporting to improve implementation.⁴⁸ If the end goal is implementation, then more detail on the development and

training of the interventionists delivering BCS, and ideally studies on the effectiveness of HCP training, should be considered.

This review has some notable limitations. First, the review contained a small number of studies that ranged in quality from weak to strong. Second, there was considerable heterogeneity in the target neurological population, HCP used as interventionists and different behavioural interventions used. Together these limitations restrict the conclusions and recommendations that may be made from this review.

In order to enhance how BCI studies can inform the training of HCP in BCS, it is recommended that future research considers including interventionist training as a standard reporting requirement. Researchers should consider implementation strategies during development of BCIs. Based on the variety of HCP trained and target neurological population, but similarities in BCS used, future studies might also consider whether training HCP to use BCS has greater efficacy when tailored to a specific disease/injury or HCP. Future research including designing and evaluating the effectiveness of training for HCP to deliver BCS is recommended.

Our findings show there is currently insufficient evidence for consensus on what should be included in and how to structure training for HCP to increase ability and use of BCS for PA with neurological populations. We have identified that future studies on designing and evaluating training for HCP on BCS for PA promotion with neurological populations and better reporting on training interventionists in BCI studies are needed to facilitate the implementation of BCS by HCP. With a growing number of studies showing effectiveness of BCS to increase PA in neurological populations, there is a need for future work to highlight the most important strategies as well as how to best implement their use into clinical practice. Individuals with neurological conditions have a lot to gain by being physically active. Preparing HCP to use BCS for PA promotion in neurological population is an important step in enhancing care for these clients.

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Chapter 5: General Discussion and Conclusion

5.1 Summary of Objectives and Key Findings

This thesis investigated the localized perspectives of PwMS and HCP working with PwMS with regards to addressing PA behaviour in the management of MS. This work took a qualitative research approach to address the gaps detailed in Chapter 1, including the need to increase the use of PA behavioural interventions in the routine management of MS, and the lack of research on HCP use of BCS for PA promotion. Further, building on the findings of the HCP and PwMS qualitative studies, a systematic review of the literature was completed. This review focused on training HCP in using BCS for PA promotion as a first step in addressing the need to improve HCP knowledge, confidence and use of PA behavioural interventions with PwMS.

Objective 1 for this thesis was to investigate the current practices and perspectives of HCP regarding PA behavioural interventions in the management of MS. Study 1 (Chapter 2) focused on this objective and found that HCP are aware of the importance of addressing PA behaviour, but feel they are not able to prioritize and successfully implement PA changes with PwMS in the current health care system. HCP expressed that successful clinical implementation of PA interventions should include: using BCS to facilitate the process of prescription; consistent messaging and promotion across disciplines, and opportunities and community programs to allow for follow up, monitoring and providing on-going expert support. These findings demonstrate that based on the experience of front line HCP working with PwMS, change is needed at the individual and health care systems level in order to improve the use of PA behavioural interventions in the management of MS.

Objective 2 was to explore the perspectives of PwMS with regards to their priorities and proposed solutions for optimizing PA behaviour in the management of MS. Study 2 (Chapter 3) addressed this objective. Findings show PwMS suggest consistent and constant messaging

regarding PA and ongoing support throughout disease progression are crucial to emphasize the importance of PA and to inform how to be physically active as individual needs change. Additionally, PwMS expressed having community programs with expert input, that clinicians are aware of and refer to, along with an increase in the number of and access to trained specialists in MS and in BCS, could enhance PA behaviour for PwMS. These findings demonstrate that the proposed solutions from PwMS are in line with the HCP perspectives findings from Study 1.

Chapter 4 was built on the need to improve HCP knowledge, confidence and use of PA behavioural interventions with PwMS that was highlighted in Chapter 2 and 3 as one priority targeting individual level change. Objective 3 (Chapter 4) was to identify and synthesize the existing literature that describes methods used to train HCP to deliver BCS for PA interventions in neurological populations, including MS. Chapter 4 found that methods used to increase HCP knowledge and use of BCS were heterogeneous. Common training features included multiple resources, multiple sessions, expert input and ongoing support, but a lack of evaluation of training effectiveness. Chapter 4 findings recommend that future work should include more description of the content and structure of HCP training and a direct measure of effectiveness, and researchers should consider implementation strategies during development and reporting of BCI.

Overall, this thesis contributed essential exploratory work confirming the need for future research and interventions to target behaviour at both the individual and health care systems (including organizational, community and policy) levels.¹ The collective findings of the three studies in this thesis highlight the importance of knowledge translation and practice change regarding PA behaviour change for PwMS and suggests that an iKT approach be used as the primary process guiding all future research.

5.2 Overlap between HCP Perspective and PwMS Proposed Solutions: Support; Training; Model of Care and Communication.

Based on the current practice and perspectives of HCP and PwMS it is evident that more focused effort is needed to utilize PA behavioural interventions in practice in ways that are meaningful and relevant to both PwMS and HCP. Such a direction is critical given the evidence demonstrating the effectiveness of PA as a management strategy for this chronic, progressive and currently incurable disease. There is noticeable overlap between the resulting primary themes of the qualitative studies involving HCP (Chapter 2) and PwMS (Chapter 3) as outlined below in Figure 5.1. The perspectives of participants showed that PwMS want to be more active, and believe that HCP have an important role in helping them achieve this goal. HCP value PA for PwMS in theory, but it is currently not prioritized in practice. The proposed solutions of PwMS highlight the gaps that were identified in the HCP study. Figure 5.1 depicts this overlap and highlights essential components found in this thesis that need to be addressed in order to influence the use of PA behavioural interventions in the management of MS. The box on the left of the figure highlights the main findings from Study 1, HCP Perspective, and the box on the right highlights that of Study 2, Proposed solutions from PwMS.

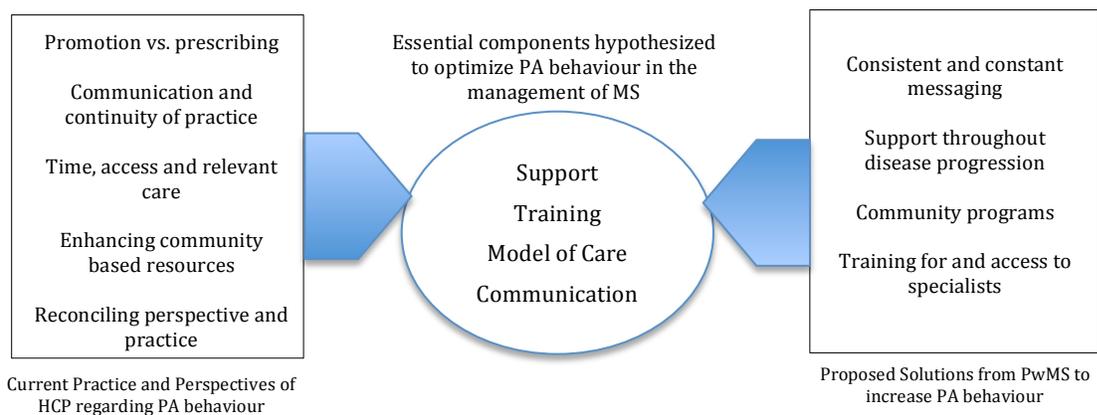


Figure 5.1 Findings and Overlap between HCP and PwMS Perspectives

The following four sections will discuss the components suggested to optimize PA behaviour in the management of MS represented in the middle circle of Figure 5.1: support; training; model of care, and communication.

5.2.1 Support

Research (as highlighted in Chapter 1) demonstrates the benefits of PA for PwMS and the importance of taking a biopsychosocial approach in addressing PA behaviour. There are consistent associations between PA levels and PA-related self-efficacy and self-regulatory constructs,²⁻²⁷ yet the findings in this thesis show the current practice of HCP does not appear to address these components in the routine management of MS. PwMS in this study reported a desire to be physically active, but find it hard to do so as their health needs change. An important component derived from the PwMS study was the need for ongoing support throughout disease progression. Similar to findings in the literature,^{28,29} PwMS want support from HCP. A unique finding in this thesis (Chapter 3) was that PwMS confirmed the need and desire for BCS to be incorporated into this on-going support from HCP.

Research shows that adherence to PA is lowest amongst individuals with chronic disease and hardest when lifestyle changes are required.³⁰ As well this difficulty may be greatest when prevention rather than cure is required, especially for individuals who do not perceive any immediate beneficial results (i.e. for those living with progressive MS.^{30,31} In order to influence PA behaviour for PwMS it is imperative to find pragmatic ways to provide support to facilitate change. The low PA levels reported for PwMS is more than an issue of adherence. Historically, adherence was thought to be too passive on the clients' end, now it appears that health care emphasizes self-management, but without providing the support needed to facilitate these skills.³² This has perhaps also contributed to being too passive on the HCP end.

HCP need to take ownership in providing the support that PwMS need and want in order to affect behaviour in meaningful ways.

5.2.2 Training

HCP need and expressed a desire for increased training on addressing PA behaviour and methods of facilitating meaningful change. Providing HCP with the skills to deliver BCS might increase HCP own self-efficacy in addressing PA behaviour and inspire taking ownership. Developing, implementing and evaluating a training program for HCP is one potential step to minimize the knowledge to practice disparity regarding the use of PA behavioural interventions for PwMS (as highlighted in the systematic review in Chapter 4).³³ There is evidence that HCP need more than simply knowing they should be promoting PA in order to successfully address behavioural components.³⁴ Similarly, PwMS need more than education about the benefits of PA in order to change behaviour.³⁵ A training program on BCS for HCP might be an important step in reconciling theory and practice. The findings from the systematic review in this thesis (Chapter 4) highlight a gap in the literature on clinical application of the outcomes of behavioural intervention studies. Investigating ways to change HCP behaviour so that they can better help influence the health behaviours of PwMS is needed.

An important component of behaviour is self-identity.³⁶ A shift in perspective on the HCP role in providing PA interventions in the routine management of MS should be emphasized. Sharing the findings of the study involving PwMS with HCP may elicit this shift in perspective so that all HCP see themselves as having a role in PA promotion and/or prescription. Further this shift might help HCP take ownership in a multifactorial situation. Findings from the HCP study (Chapter 2) highlight systemic, time and resource barriers, but individual HCP ownership can help ignite a change in practice.

5.2.3 Model of Care

Reference to a reactive, rather than proactive health care system was made often by both HCP and PwMS. The reactive health care system appeared to influence HCP' treatment priorities and the ability to effectively target PA behaviour for PwMS. However, evidence is ample that increased PA levels address many of the impairments and priorities HCP described (e.g. function, symptom management).³⁷⁻⁴³ HCP need to acknowledge in practice that PA can be more than just structured exercise. It has many levels and can be used to target numerous complaints/priorities that the HCP seem to be focusing on in 'reactive' approach. This re-thinking of PA paired with HCP taking ownership of what can be done in the current system to affect PA behaviour could have substantial impact for PwMS and the role of HCP in systems level change. HCP must emphasize their role beyond just the client-provider relationship in order to become advocates, coaches, and community liaison that will comprehensively address the biopsychosocial components essential to affecting change.⁴⁴

Systemic barriers do exist and should not be overlooked. Long waitlists, minimal opportunity for follow up, poor communication and resources limitations were some of the barriers highlighted by HCP as important determinants of their clinical approach. Further, PwMS expressed the need for better access to specialists and MS specific care. Seeing the overlap between HCP and PwMS perspectives strengthens the need for system levels change at the institutional, community and policy levels. New models of care focused on maintaining wellness and quality of life rather than responding to acute illness have yet to be applied to routine MS care.⁴⁵ Systems level change would still require HCP ownership, but may facilitate the ease of application providing support for HCP while emphasizing accountability. Systems level change has also been emphasized by a provincial MS advisory panel.⁴⁶ The report of this

panel reinforces the findings of this thesis emphasizing main systemic issues include a lack of: training for and access to specialists; local supports; timely follow up, and coordination of care.

Systems level change could be informed by other chronic disease models such as diabetes, arthritis and heart disease.^{47,48} These models have established pathways of care and emphasize providing multidisciplinary support, facilitating lifestyle behaviour change through action planning and developing self-management skills, and through community programming. Gathering the lessons learned from models that have been in place allows for the identification of their successes, limitations, and failures. Such knowledge could inform initial decisions about what to change in the system and whether the system is amenable to change.

There is a need for decision makers in the health care system, researchers, HCP and PwMS to come together to identify community interventions most appropriate to meet the needs of end users. The development of future resources should not be done without considering communication of resource and evaluation of their implementation (i.e. are end products getting used and serving the need they were designed to address).

5.2.4 Communication

Communication and understanding across all stakeholders are fundamental to being able to affect change. PwMS want constant and consistent messaging about being physically active which requires HCP to HCP communication to be improved. HCP want to know about resources and multidisciplinary HCP with expertise in MS that they can refer to. As community resources are developed, there needs to be a means to consistently provide up-to-date information about the resources to HCP. The Ministry of Health, Health Authority and MS Society all have a role in providing resources and also improving communication about their use, further supporting taking an integrated knowledge translation process to future research.

This process will facilitate communication and also ensure that as interventions and resources are developed and researched that necessary communication channels important to this implementation and evaluation are in place. As research on the importance of PA, effective behavioural interventions and applying chronic care models to MS evolve, it is important they do so in a manner that will maximize clinical application.^{49,50}

This thesis contributes a wealth of new knowledge emphasizing the localized current practice and perspectives of PwMS and their HCP with regards to PA behavioural interventions in the management of MS. The problem is greater than just low PA levels – care needs to be improved. PA as a management strategy does not exist in isolation. There is no one solution; multiple viewpoints are important and learning from lived experience is needed. It is a collaborative effort.

This thesis highlights that solutions are complex and multifactorial. Individual level change is required. HCP taking ownership may support a shift to all HCP acknowledging their role as PA promoters. Preparing certain HCP as prescribers and enhancing their knowledge, confidence and use of BCS needed to effectively apply comprehensive biopsychosocial interventions. Individual level change and advocacy may augment systems (institutional, community and policy level) change. The use of community engaged and integrated knowledge translation approaches also have the potential to influence systems level change. Systems level change may be accomplished by using the lessons learned from other more developed chronic disease models. A community-based approach to provide expertise and access to the on-going support is needed. The networks created through these approaches have the potential to enhance communication and the development of solutions that are meaningful and relevant to all stakeholders particularly PwMS and HCP as the targeted end users.

There is a great deal still to be learned in the research regarding PA in the management of MS, but with health care being an applied science there is even more to be gained (e.g., improvement in PwMS function) from putting what is known into practice now. The findings of this thesis highlight the importance of knowledge translation of the science of behaviour change regarding PA behaviour engagement and maintenance for PwMS.

“[PA] adherence cannot be expected to occur on it’s own or because we wish it, and it is too important to leave to chance” Meichenbaum & Turk (pg 12)

5.3 Limitations and future research

Overall, the qualitative studies in this thesis included a small number of participants (Chapter 2 and 3) and were exploratory in nature. However, the number of participants allows for the strengths of qualitative research to be emphasized including a depth and richness of shared knowledge.⁵¹ This sample size may limit the generalizability of findings, but emphasizing localized knowledge is a strength as this approach potentially identifies what might be the most meaningful next steps in both local research and practice. SK has one of the highest rates of MS worldwide⁵² and localized research allows any unique needs of SK to be identified.

Chapter 4 (systematic review) addressed only one component, at the individual level of change, suggested by the findings of the qualitative studies in this thesis. Major limitations to this review were the small number of studies included, and the variable type of studies included. These made drawing conclusions to inform the development of a training for HCP on BCS for PA for PwMS difficult.

Future research, informed by this thesis, should have three broad goals. First, take an integrated knowledge translation approach to efforts to address a change in behaviour at all levels – the individual (PwMS, the HCP), and the health care system. Second, research should

aim to engage a broader sample of PwMS and HCP across Saskatchewan. Third, research needs to be conducted that (a) leads to the HCP at an individual level being agents of change themselves and to (b) inform and implement system level change.

With respect to part (a) of the third goal, iKT research focused on the HCP could examine training programs for the HCP in order to increase knowledge, confidence and use of BCS in neurorehabilitation (to reconcile theory and practice). As well, research on improving care, communication, and/or coordination of care should also include family practitioners and further input from rural HCP. Regarding part (b) of the third goal, systems level change is needed and could be facilitated by research to inform the development of a Provincial MS Care Pathway, providing expertise and/or specialization in MS, and innovative methods of delivering chronic care support.

5.4 Overall Conclusion

This thesis demonstrated an exploration of the perspectives of PwMS and HCP working with PwMS in SK with regards to PA behaviour change. Further, the literature was systematically searched regarding training HCP in using BCS for PA promotion as a first step in addressing the need to improve HCP knowledge, confidence and use of PA behavioural interventions with PwMS. Training HCP is a starting point and is one approach at the individual level to improve PA behaviour change in MS.

Changing behaviour is complex and multifactorial. The findings of this thesis show that future efforts (both research and interventions) need to acknowledge that there are barriers to utilizing PA behaviour change for PwMS at several levels, and work is needed at each of these levels in order to implement change. Taking an integrated knowledge translation approach to further the next steps in research is recommended to promote concurrent and complimentary

change needed at the individual, interpersonal, organizational, community and policy level.

Future efforts should target key factors identified in Figure 5.1 (support, training, model of care and communication) to address localized priorities, to maximize potential applicability to end-users and to effect meaningful change.

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Appendix A. Search Strategy Table 1.1

Table 1.1 summarizes reported correlates and determinants of PA for PwMS. It was created based on the quantitative studies identified through two existing systematic reviews (Streber et al., 2016;¹ Casey et al., 2017²) and an updated (March 2019) literature search conducted to inform this thesis. Firstly, Streber et al. 2016¹ published a paper titled “Systematic Review of Correlates and Determinants of Physical Activity in Persons with Multiple Sclerosis”. This paper included 56 publications (54 observational; 2 intervention) published prior to Jan 2015. The 56 studies identified in Streber et al., 2016¹ were then compared to the 26 studies (22 observational; 4 intervention) included in a 2017 publication by Casey et al.² titled “Modifiable Psychosocial Constructs Associated With Physical Activity Participation in People With Multiple Sclerosis: A Systematic Review and Meta-Analysis”. 22 studies were duplicates from the 2016 review, leaving 4 (1 observational; 3 intervention) newly identified studies from the 2017 review. Further, a literature search was conducted (update March 2019) to inform this thesis. Keywords included: physical activity, exercise, multiple sclerosis, behaviour change strategies/techniques, behaviour change interventions, behavioural determinant/correlate/barrier/facilitator. This search yielded 256 studies with an additional 12 observational studies included.

¹Streber R, Peters S, Pfeifer K. Systematic review of correlates and determinants of physical activity in persons with multiple sclerosis. *Arch Phys Med Rehabil.* 2016;97(4):633-45.

²Casey B, Coote S, Shirazipour C, Hannigan A, Motl R, Martin Ginis K, et al. Modifiable psychosocial constructs associated with physical activity participation in people with multiple sclerosis: a systematic review and meta-analysis. *Arch Phys Med Rehabil.* 2017;98(7):1453-75.

Appendix B. Copyright Permissions



Title: Informing the training of health care professionals to implement behavior change strategies for physical activity promotion in neurorehabilitation: a systematic review

Author: Donkers, Sarah J; Chan, Katherine

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Appendix C. Supplementary Material (Chapter 4)

Appendix C.1 Medline Search Strategy Systematic Review

Database: Ovid MEDLINE(R) ALL <1946 to September 11, 2017>

Search Strategy:

- 1 exp Nervous System Diseases/
- 2 (Multiple Sclerosis or Parkinson*).tw,kw.
- 3 ((neuro* or nervous or neural*) adj3 (disease* or condition* or disorder* or syndrome* or dysfunction*)).tw,kw.
- 4 or/1-3
- 5 exp Behavior Therapy/
- 6 ((behavior* or behaviour*) adj3 (therap* or modif* or chang* or intervention* or strateg* or technique* or treatment* or training)).tw,kw.
- 7 5 or 6
- 8 exp Health Personnel/
- 9 exp Evidence-Based Practice/
- 10 Translational Medical Research/
- 11 Clinical Competence/
- 12 exp Counseling/
- 13 ((health or medical or physical) adj3 (therap* or professional*)).tw,kw.
- 14 (research adj3 (emerg* or evidence)).tw,kw.
- 15 (translation* adj3 (knowledge or research)).tw,kw.
- 16 (knowledge adj3 (translat* or transfer* or framework* or uptake or action* or process* or mechanism* or practitioner* or disciplin* or scientific* or applic* or utilisation* or utilization* or disseminat* or implement* or integrat*)).tw,kw.
- 17 (evidence* adj3 (practic* or health or healthcare*)).tw,kw.
- 18 (professional adj2 (help or counsel*)).tw,kw.
- 19 or/8-18
- 20 Motor Activity/
- 21 exp Exercise/
- 22 exp exercise movement techniques/
- 23 exp exercise therapy/
- 24 recreation therapy/
- 25 dance therapy/
- 26 exp Sports/
- 27 (physical* activ* or exercis*).tw,kw.
- 28 (training adj3 (gait or exercise* or physical*)).tw,kw.
- 29 or/20-28
- 30 4 and 7 and 19 and 29

Appendix C.2 Supplementary Data Extraction Table Systematic Review

The supplementary table can be downloaded from the original article published online: Sarah J Donkers, Katherine Chan, Stephan Milosavljevic, Maureen Pakosh, Kristin E Musselman, Informing the training of health care professionals to implement behavior change strategies for physical activity promotion in neurorehabilitation: a systematic review, *Translational Behavioral Medicine*, iby118, <http://doi.org/10.1093/tbm.iby118>